

The BurnNet News

May 2020, Volume 39, No. 5

BURNNET SURVIVOR MEETINGS GO VIRTUAL!

Thursday, May 7 -- 7:30-9:00pm



While we are all following the guidelines for physical distancing as recommended, this is NOT the time to be socially disconnected. Many of our burn survivors feel anxiety or sadness from being separated from seeing friends or loved ones. Compounded by your fears and questions regarding your burn recovery journey, this really can be a difficult time.

But now there is something you can do about it! The BurnNet Survivors will resume our monthly meetings to discuss issues and raise questions related to burns using the ZOOM format through the generosity of the Firefighters Burn Institute. Interested burn survivors, family members and significant others must pre-register.

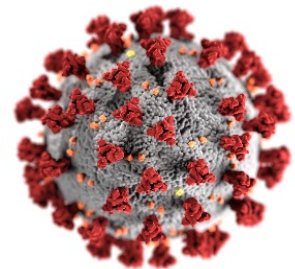
[Here is the link to the Google form for meeting registration](#)

For more information, call Deb Jones RN at (916) 734-5596 or debjones@ucdavis.edu

BURN SURVIVORS + COVID-19: ARE YOU MORE AT RISK?

As communities worldwide practice social distancing to slow the spread of COVID-19 (coronavirus), many burn survivors are wondering if they are at a greater risk. We connected with Dr. Victor Joe, a burn surgeon and Phoenix board member, to learn more.

According to Dr. Joe, there is a growing need to understand how a burn injury affects long-term health. There's still a lot we don't know about how burns impact the development of chronic disease—and there's a lot we don't know about coronavirus.



HERE'S WHAT WE KNOW:

- All individuals are at risk for COVID-19. Because the virus is new, no one has immunity.
- There is no information to suggest COVID-19 infection can occur via open skin wounds. Infection doesn't occur via exposure to skin itself, but through contact with mucosal surfaces like eyes, nose, and mouth. (This is why it's important to avoid touching your face as much as possible.)
- People with previous burn injuries may be at higher risk of cardiovascular diseases, diabetes, and respiratory infections. Dr. Joe cites the need for broader population-based studies to validate these findings.
- The Center for Disease Control (CDC) lists the following groups as high-risk for severe illness of COVID-19:
 - People 65 years and older
 - People who live in a nursing home or long-term care facility
 - People of all ages with underlying medical conditions, particularly if not well controlled, including:

- People with chronic lung disease or moderate to severe asthma
- Past prolonged need for mechanical ventilation for inhalation injury and respiratory failure may lead to chronic lung disease. A current medical assessment is necessary to diagnose chronic lung disease.
- People who have serious heart conditions
- People who are immunocompromised

Many conditions can cause a person to be immunocompromised, including cancer treatment, smoking, bone marrow or organ transplantation, immune deficiencies, poorly controlled HIV or AIDS, and prolonged use of corticosteroids and other immune weakening medications

- People with severe obesity (body mass index [BMI] of 40 or higher)
- People with diabetes
- People with chronic kidney disease undergoing dialysis
- People with liver disease

WHAT DOES THIS MEAN FOR BURN SURVIVORS?

Based on what we know now, Dr. Joe believes burn survivors, especially those who survived major burn injuries, are at higher risk for development of severe disease to the extent they have the risk factors listed above.

“For me, the factor that is most unclear in terms of burn injury and COVID-19 is that of immune compromise,” says Dr. Joe. “I do not think we understand the extent and/or persistence of immune suppression burn survivors have and its potential relationship to burn size.”

HOW CAN YOU STAY HEALTHY?

With more questions than answers, it can be hard to know how to stay safe. Here’s what Dr. Joe recommends:

- Strict adherence to social distancing and hand hygiene
- Follow CDC guidance on masking
- Monitor closely for symptoms: fever, cough, shortness of breath
- Seek medical attention if you have:
 - Trouble breathing
 - Persistent chest pain/pressure
 - A fever of 100.4 degrees or above
 - New onset of lethargy or confusion
 - Blue color of lips or face (The latter two are signs of low amount of oxygen in the blood.)

To learn more about protecting yourself and others from COVID-19, check out the CDC's [guidelines](#).

Reprinted with permission from The Phoenix Society Written on April 8, 2020

<https://www.phoenix-society.org/resources/burn-survivors-covid-19?fbclid=IwAR2x8EauA-iRaxzIrlIDEJ7qrj5Avc8BkGwu6jz-N9z7nKT032kRTOaeb-c>



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Email Deb Jones RN at debjones@ucdavis.edu

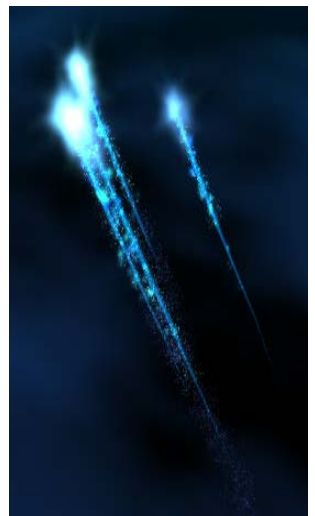
You can also find The BurnNet News at our website:

www.ucdmc.ucdavis.edu/burncenter/newsletter/index.html

QUOTE

There is a Latin saying going back 2000 years: “per aspera ad astra” which translated means “through adversity to the stars”. So, whenever an obstacle rises that seems to block the path forward, in reality the obstacle has an essential function. And that is, it forces me or it forces humanity to generate more — either more strength, more energy or more consciousness.

~ Eckhart Tolle, author and spiritual teacher



MOVEMENT CONTROL ORDER FROM THE VIEW OF A BURN SURVIVOR

When the government announced a 14-day Movement Control Order (MCO) throughout Malaysia because of the coronavirus, chaos and panic happened at the supermarkets, despite the government's assurance of enough food and daily necessities. The government thought that the message was clear, everyone was to stay home, social distancing from one another.

However, on the first day itself, some defied the MCO and continued with their merry ways, not taking this pandemic seriously. Now, the fourteenth day has passed, and the government has extended the MCO until the 14th of April as the numbers of those infected within the country become higher.

This is not the first time I am being confined to a place; like a bridge between two stories, I can't help but to compare and connect it to my post-burn care experience.

The feeling of isolation, uncertainty for the future, unpredictability, anxiety, hopelessness, not being in control, fear, confusion regarding the situation and most of all, not seeing the light at the end of the tunnel. These are the emotions that most normal Malaysians must have been having when they were suddenly being restricted to their own homes.



I remember being in physical discomfort and pain nearly every day after getting out from a medically-induced coma. The pain was unbearable during dressing change. The first time I consciously experienced this, it was over two and a half months after the explosion. An unforgettable morning, 10 to 12 hospital staff, including doctors and nurses suddenly barged into the room. I was confused and partly delirious. Covered from head to toe with bandages, I didn't know what was going on. They positioned themselves on every corner of my bed, talking among themselves. Then suddenly, they removed my bandages on every part of my body. It felt like they ripped my skin off. I felt the pain three times: during removal of primary dressing, cleaning of wound and finally during the application of medicine. I heard a petite middle-aged lady giving orders to the other doctors and nurses to do it efficiently and as fast as possible. I was crying in agony.

A male doctor was removing the bandage on my head, "we need to keep the donor area clean". He was talking about my head. I was shocked! Donor area? What did they take from my head? My hair? I tried to protest but the words couldn't come out from my mouth, they couldn't understand me. Confusion overwhelmed me. They could only see my tears and hear some inaudible noises. They had punctured a hole in my throat to insert a tracheal tube, so a machine (ventilator) could breathe for me whenever needed. At that moment in time, I didn't know I had 80% burns to my body. They had taken the skin from my scalp for grafting and transferred this skin to my hands.

Instead of viruses, most burn survivors worry about bacteria. The burn area, unprotected by skin, has a high risk of being infected. A hospital can be a breeding ground for bacterial infection. During my stay at the ICU, I became infected with CRE, a type of bacteria, resistant to antibiotics. Dying of blood sepsis can happen in an ICU. In the burn ward, I was treated for MRSA 4 times. There were a few instances, the doctors thought I wouldn't survive.

Looking back, there were times I felt the pain and suffering would never end. Doomed to be like a ghost experiencing the same painful incident just before death over and over again. Some days were overwhelming, it felt like taking one step forward, and the next day two steps back.



In moments of difficulties, a friend reminded me to be grateful; to appreciate my family and the people around me, to accept my condition and surrender whatever I couldn't control to others. Concentrating on what I could do instead of what I couldn't was probably the most difficult thing I had to do. My mind was the only thing I had, not my physical body. Being immobile, even my fingers were stiff and painful to the touch. To survive, I had to concentrate on being positive. Convincing myself that even though I was in pain, I was getting the help I needed. Constant reminders came from my sister. I was getting better every day, even though I was not feeling it.

A burn survivor faces his/her pain alone or with his/her own family members or community, whereas coronavirus (Covid-19) affects everyone. During this hardship, we need to strengthen our minds. If we are not clear headed enough or calm enough, we will fall into a black hole of darkness which threatens to swallow us whole.

Instead of complaining, living in fear and viewing things negatively, concentrate on what we can do at home, be creative. If we have been procrastinating on certain projects with an excuse of not having the time to do so, this is the time to complete it. Even with the restriction in movement, we can always be thankful for what we have, for there are others who have less.

During this period, we can see the best and the worst in people. On one side of the coin, hardship and suffering can make a person become bitter, losing hope and blaming others for their misery, resorting to crime, etc. However, on the other side, there are people who remain caring, compassionate and helpful despite experiencing the same situation.



We are not facing this problem alone. It is a pandemic that is affecting the entire world. It is time for everyone to help each other. Unlike humans, the COVID-19 does not discriminate. The world needs to cast aside any differences in race, religion, gender, social and economic status; this is a fight for humanity.

Our good values are the foundation of what makes us decent and rational human beings. If we disregard our values during this time of crisis, in the process of slaying this invisible beast, we might end up becoming a beast ourselves.

By Eileyn Chua, burn survivor – written March 31, 2020.

April 15 is the 4-year burniversary since a gas explosion caused 80% burn on my body.

OTHER SUPPORT OPTIONS



Phoenix Society for Burn Survivors

Find support and connection whenever you need it, wherever you are through Phoenix Society's active online community.

1. **Virtual Support Groups** - Held every Monday; schedule alternates to accommodate different time zones, please pass on and check it out here: <https://www.phoenix-society.org/what-we-do/virtual-support-group>
2. **Peer Support Chat** – Occurs every Wednesday evening, please pass on and check it out here: <https://www.phoenix-society.org/what-we-do/peer-support-chat>
3. **Peer Support Office Hours** – this will be an informal time for survivors, families and healthcare to come together for social interaction. We will open a space, details coming soon for the community to connect. We will share additional details on our [Facebook Page](#) and at www.phoenix-society.org/connect when available.
4. **Youth and Family Virtual Group** – will occur every Wednesday afternoon and include a virtual group activity and a young survivor sharing their story. Additional information and a sign up form will be added to www.phoenix-society.org/connect when available.
5. **Facebook Live Videos and Webinars** - Throughout the next few weeks, we'll be hosting a variety of digital events, including Facebook Live Videos and webinars. We'll be updating www.phoenix-society.org/connect frequently with the latest updates and dates.
6. **Resource Center** Peer supporters, survivors, families; inpatient, in the clinic and in the community are encouraged to explore the updated Resource Center. It has a growing collection of survivor stories, fact sheets, online courses, and more at <https://www.phoenix-society.org/resources>.
7. **NEW! Burn Community Drop-In** - Phoenix Society is excited to share a new virtual connection opportunity for the community, called Burn Community Drop-In. Every Tuesday from 12-12:30 pm PST. Every Saturday from 9 -9:30 am PST. You can learn more about Drop-In here: <https://bit.ly/2Ro7DSD>. The intention for the time (30 minutes) is to provide a space where people can check in, say hi, see how others are doing, etc. Imagine this as functioning like what people would talk about at a neighborhood picnic or at the coffee shop. Click on this link to sign up: <https://bit.ly/2ywEM7Y>.

UPCOMING EVENTS



June 27 9th Annual Firefighter's "A Tropical Affair"

Come and enjoy an evening out with Sacramento's finest restaurants, breweries and wineries for a great cause! This outdoor event will be held at the lawn behind Shriners Hospital for Children in Sacramento, CA. Live music entertainment, Hawaiian hula dancers, local celebrities as MCs, and a variety of foods and beverages provided by generous local business sponsors from the Sacramento area, all included in the price of admission. Tickets are \$60 or \$100/2 tickets. Don't wait to buy your tickets! If we don't sell out, tickets at the door will increase to \$75/ticket. **Purchase tickets [here!](#)**



AUGUST 8 - HANDLE WITH CARE MESSAGE

Jen Hartley is a Nationally Certified Massage Therapist and Burn Scar Massage Therapy CEU provider. She will be holding a Burn Scar Massage Training for Massage Therapists and will be looking for burn survivors from our area to volunteer for these therapists to practice their newly learned skills.

Time: 8:30am-5:30pm

Contact Jen at: Phone: 706-831-2889 or 213-660-5106 or Email: HWCMassage2004@gmail.com

19 THINGS TO REMEMBER ~Reflections, Dave and Mike Radparvar

- 1) Remember to dream big
- 2) Remember that it's OK if life doesn't go to plan
- 3) Remember that this moment is precious
- 4) Remember to not take yourself too seriously
- 5) Remember to say yes to adventure
- 6) Remember to value the things you have
- 7) Remember to value the relationships you have
- 8) Remember that life is challenging
- 9) Remember that challenges can be good
- 10) Remember that no one has it figured out
- 11) Remember that we are all in this together
- 12) Remember that you need to take responsibility for your actions
- 13) Remember that things are constantly changing
- 14) Remember that you can be a force that changes things
- 15) Remember to get out of your comfort zone
- 16) Remember to lead with love
- 17) Remember that even the haters need love
- 18) Remember that the world reflects back the vibes you put out
- 19) And always remember that you are enough

Remember

SOME INSPIRATION TO KEEP YOU AFLOAT WHEN LIFE FEELS UNSTEADY

Years ago, when I was going through some big shifts in my life, a friend sent me a beautiful excerpt. Sometimes we forget the power of transformation - allowing our preconceived notions of what is, to dissolve and giving our spirits permission to come together again, anew. It's scary when life pushes us forward before we've had a chance to program our GPS. It's unsettling to be hanging in the balance when we're unsure where we are going to land. It often forces us to find a bravery within that we never knew existed!

That part can be empowering :) But it's not always easy when we are in the thick of it! How do we survive that tumultuous interlude when it feels like things are falling apart? What can we do to hold on to our sanity while our foundation is shifting? How can we learn to keep our faith that it's all going to be OK?



I found this passage to be an incredibly inspiring perspective on the Magic of Transition and Transformation:

TRANSFORMATION from the *Essence Book of Days* by Danaan Parry

"Sometimes I feel that my life is a series of trapeze swings. I'm either hanging on to a trapeze bar swinging along or, for a few moments in my life, I'm hurling across space in between trapeze bars. Most of the time, I spend my life hanging on for dear life to my trapeze-bar-of-the-moment. It carries me along a certain steady rate of swing, and I have the feeling that I'm in control of my life. I know most of the right questions and even some of the right answers.

But once in a while, as I'm merrily (or not so merrily) swinging along, I look ahead of me into the distance, and what do I see? I see another trapeze bar swinging toward me.

It's empty, and I know, in that place in me that knows, that this new trapeze bar has my name on it.

In my heart-of-hearts I know that in order for me to grow, I must release my grip on the present, well-known bar to move to the new one.

Each time it happens to me, I hope (no, I pray) that I won't have to grab the new one. But in my knowing place I know that I must totally release my grasp on my old bar, and for some moment in time I must hurtle across space before I can grab onto the new bar. Each time I am filled with terror. It doesn't matter that all my previous hurtles across the void of unknowing I have always made it.

Each time I am afraid I will miss, that I will be crushed on unseen rocks in the bottomless chasm between the bars. But I do it anyway. Perhaps that is the essence of what the mystics call the faith experience. No guarantees, no net, no insurance policy, but you do it anyway because somehow, to keep hanging onto that old bar is no longer on the list of alternatives.

And so, for an eternity that can last a microsecond or a thousand lifetimes, I soar across the void of "the past is gone, the future is not yet here." It's called transition. I have come to believe that it is the only place that real change occurs. I mean real change, not the pseudo-change that only lasts until the next time that my old buttons get punched.

I have noticed that, in our culture, this transition zone is looked upon as a "no-thing" a no-place between places. Sure, the old trapeze bar was real, and the new one coming towards me, I hope that is real too. But the void between? That's just a scary, confusing, disorienting "nowhere" that must be gotten through as fast and as unconsciously as possible. What a waste! I have a sneaking suspicion that the transition zone is the only real thing, and the bars are illusions we dream up to avoid the void, where the real change, the real growth occurs for us. Whether or not my hunch is true, it remains that the transition zones in our lives are incredibly rich places. They should be honored, even savored.

Yes, with all the pain and fear and feelings of being out-of-control that can (but not necessarily) accompany transitions, they are still the most alive, most growth-filled, passionate, expansive moments in our lives.

And so, transformation of fear may have nothing to do with making fear go away, but rather with giving ourselves permission to "hang-out" in the transition between the trapeze bars. Transforming our need to grab that new bar, any bar, is allowing ourselves to dwell in the only place where change really happens. It can be terrifying. It can also be enlightening, in the true sense of the word. Hurling through the void, we may just learn to fly."

~Meredith Blis