

# Burn Support Magazine

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## Writing Your “Someday” List

# Jill Sproul and Kevin Cook: A Story of Hope

By James Bosch, MA

*Does everything really happen for a reason? How does someone maintain hope in the face of a devastating trauma? These are two of the biggest questions faced by many burn survivors and their immediate caregivers. This article addresses both questions through the lens of a love story, the story of how Jill Sproul and Kevin Cook lost much but found each other. It aims to plant a tiny seed of hope so that no matter how desperate things may seem, you can know it is still possible for your life to change in ways you had never dreamed. It is still possible for your “someday” to be full of love, happiness, and opportunity.*

Jill Sproul’s burn journey began on a chilly morning at a campground in Northern California. It was March 27, 1972. Jill was 7 years old and the youngest of three girls. She and her oldest sister, Chris, decided they would get up early and surprise their parents with breakfast. They had difficulty getting the fire started, so 12-year-old Chris grabbed what she thought was lighter fluid to help things along. What she had in fact retrieved was gasoline, and in a flash both girls were on fire. Chris stopped, dropped, and rolled, which extinguished the flames. Jill, younger and frightened, ran. While Chris sustained third-degree burns over 35% of her body, Jill’s injuries were more severe—65% of her body had been seared. When Gene and Shirley Sproul came running out of their tent, they encountered a horrific scene, a scene that would bring about change for the entire family.

Jill’s initial 4-month hospital stay was full of pain and unpredictability. Her mother ran between two hospital rooms and two injured children; her father took care of the home, the dogs, and the couple’s middle daughter, Kelly, who was not injured.

Jill recalls the painful dressing changes, blood draws, cold bed pans, and the anxiety caused by not knowing what would happen next. All of this was compounded by the end of Jill’s daily life as she knew it. “Everything was going on without me, and I was missing out,” she recalls. “Everything seemed so uncertain.” It would take many pages to chronicle the long journey of facial reconstructions, donor sites, medical procedures and complications, bad wigs, pressure garments, etc., that followed.



**Kevin and Jill, who were married in 2005, are still adding to their “someday” list.**

Jill’s parents were her rocks, and the family in turn was fortunate to have a lot of community support, as well as a great team of doctors and nurses. When it was finally time for Jill to leave the safe bubble of the hospital, she was afraid to face her peers with her altered appearance. She remembers making a pact with herself that she was going to be strong, that she would not show any weakness. This worked in her insulated world of family, friends, and school. It helped that she had been very social before her injury; now all of those friends were there for her when she was eventually able to return home. School re-entry programs didn’t yet exist, so Jill’s mother went to the school and talked about what had happened to her daughter. Shirley showed Jill’s classmates the pressure garments she would be wearing and helped to create an atmosphere of acceptance.

Jill recalls that the hardest moments were when she went to the mall or to the movies and had to deal with the hostile stares and bullying comments of strangers. Her resolve to be strong would waiver, yet her tribe

of friends was always there to support her. "Someone always had my back," she says.

It was a different story when Jill got to high school, where her days were filled with D's and F's. These D's and F's were not the kind you find on a report card—Jill continued to do well academically. They were the D's and F's that plague a new burn survivor: disfigurement, dieting, dating, dealing with peers, dealing with reconstructive surgery, fear of failure, fitting in and having fun. Jill believed, as many teenagers do, that if she were skinny people might not notice her disfigurement. So she tried all kinds of fad diets. It's an example of how a survivor may try to control an area of his or her life to compensate for feeling out of control in other areas. But Jill says her behavior only led to her becoming very unhealthy and looking like a "too-skinny burned girl."

When Jill started dating, she had some good experiences, as well as some bad ones. At one point she decided that maybe dating, marriage, and kids were not in the cards, and she dove into academics. "I thought, if I can't have a family I will have a great career," she explains. After high school graduation, Jill enrolled in nursing school, inspired by all the wonderful nurses (and some of the not-so-good ones) who had taken care of her. Jill landed a job in a burn unit, enabling her to achieve one of her proudest accomplishments, becoming a burn nurse.

Her "someday," however, was still to come.

Kevin Cook's burn story began when he was a little older. His early life was one of change, resiliency, and adaptation, three qualities Kevin feels helped him cope with his devastating burn injury when it occurred. Kevin is the child of a Vietnamese mother and American soldier father, who met during the heart of the Vietnam War in 1963. As a military brat, Kevin had to move every 2 years and often to different countries, where he had to open his mind and heart to new people and new experiences. It also taught him the importance of family, another quality that would help him cope with his eventual injury.

Kevin, who had an older sister, gained a brother when his parents adopted a boy. Then after a move to Thailand, the family added two more adopted children. The family would continue to grow when, while they were living in Thailand, Kevin's mother courageously traveled to Vietnam seeking to sponsor as many children as would be allowed in order to get them out of the country as it began to fall to the communist regime. After the family returned to the U.S., 6 children whom the family had sponsored eventually arrived in California, via the Philippines, to join them. With these 10 brother and sisters, Kevin never lacked love and companionship, and each time the family moved, a little city moved with them!

The family eventually settled in Northern California. Kevin was very active and social in school. Although he always struggled academically, he excelled in sports and

was often featured in the local paper for his football triumphs. It was in high school, when he was accidentally enrolled in a welding class, that he was introduced to his calling and the eventual cause of his injury.

The moment Kevin began his first project he knew that welding was what he wanted to do with his life. Welding and fabricating became not only his career, but his passion. When he was not welding at work, he was fabricating a project on the side in his free time.

Kevin was equally focused on his personal goals, which including owning a house, getting married, and having children, all by the time he turned 30. He achieved the first of these when, at 23, he bought a home. Everything continued to go as planned—before that milestone of 30 he had a home; had met and married his first wife with whom he had two beautiful children, Kayli and Jordan; and enjoyed a very active lifestyle that included boating, barefoot water skiing, scuba diving and free diving, and big family gatherings on the weekend.

However, on August 28, 1997, everything changed. On this particular Thursday, Kevin was working at a remote welding site when something went terribly wrong. During a routine industry-practiced procedure that he had performed 55 times previously, a vacuum that would have kept diesel fuel in the tank was lost. Kevin was soaked by the fuel, which ignited. Normally Kevin would have been at the site alone and would surely have perished, but fortunately a coworker arrived earlier than usual, saw Kevin, who was on fire, jump down from the machine, and sprayed him with a fire extinguisher.

Kevin remembers everything from the time he caught on fire until he was rolled into the local burn center. He had no idea how bad things were, and being a hard worker, all he could think about was that he had ruined his perfect work safety record and would probably have to cancel his weekend ski trip. Then Kevin learned that he had burns over 85% of his body. In fact, the fire was so hot that Kevin's feet were burned by the steam his sweaty socks had produced in his boots.

Kevin underwent more than 20 procedures during his first hospitalization, spending his 31<sup>st</sup> birthday in the hospital. He received overwhelming support from his large community of friends and family, including his mother, Lee, who was by his side every day. Kevin's excellent physical health before the injury, coupled with his stubborn determination, helped him achieve his goal of being home by Thanksgiving. In fact it was precisely on Thanksgiving Day that Kevin was discharged, just 90 days after his injury.

It's at this point that Kevin feels the more challenging parts of his recovery began. Back at home, away from the support of the burn center, Kevin struggled with being idle. He was accustomed to working up to 70 hours a week, but now he had a lot of "stagnant" time. During the first year

of recovery he also struggled with all the unanswered questions and new challenges: Would he be able to return to the work he loved and when? How could he make plans for his life with an uncertain surgery schedule and countless hours of therapy ahead? Would the legal battles ever end? And then there was the heavy grief over losing the function of his hands, his main tool, and feelings of sadness about the lack of touch and the disintegration of his marriage. And everything was intensified by Kevin's chronic physical pain and constant itching.

Losing his livelihood, his dreams, and his marriage, combined with the impact of financial and legal issues, began to take a toll. Kevin needed some hope. He found books on burn recovery, which were helpful, but what really drove Kevin to recover was his children, as well as the peer support offered by the local burn support group and burn foundation. Kevin reached deep into his reserves of natural optimism and adaptability. Getting involved in the Phoenix World Burn Congress (WBC) and other burn support programs helped Kevin to start to see the possibility of a second chance at his "someday."

*Little did Kevin and Jill know that their "someday" was just around the corner.*

Jill and Kevin's lives finally intersected at Phoenix WBC, as well as local burn events, where a warm and supportive friendship developed. Kevin's marriage was deteriorating. He and his wife were now living as roommates and moving toward separation. Jill had just escaped a very unhealthy relationship. Both were wondering if a loving relationship was in the cards for them. As their friendship grew, a mutual friend (me) put a bug in Jill's ear by asking, "Hey, what about you and Kevin?" It didn't take long for the two to realize they were meant to be together, and their friendship developed into a courtship and finally into love. And then, their "someday" wishes merged and became a reality.

Jill and Kevin were married on April 16, 2005. They have a son, Tyler, and a daughter, Meghan. They are currently working on the next phase of their lives by adding more to their "someday" list. They have a home, which is the meeting place for their friends and their families, and they are very involved in the burn community. By giving back and giving other burn survivors hope, Jill and Kevin live their story. It is a gift of hope for all burn survivors, young and old, who live with the belief that because of their disfigurement or situation they will never have a loving relationship or a family. Jill and Kevin share their "How to Have Hope" list:

- Be optimistic. Strive to see the glass as half full.
- Be open-minded.
- Be willing to reach out to others and to ask for help when needed.
- Help others.



**Keeping family a priority—From left to right: top row, Kevin and Jordan; bottom row, Jill, Tyler, Kayli, and Meghan.**

- Find new passions to replace the ones you have had to let go.
- Don't give up on finding new ways of dealing with chronic pain and itching.
- Get involved in peer support and the burn community.
- Keep family a priority.
- Set and look forward to new goals.

They encourage others to open up their hearts to the possibility of love, even if it first leads to heartache. It took them a while to find each other, and the journey helped make them each who they were when they finally crossed paths. Jill reminds everyone, "Hope costs nothing, but hopelessness can cost you everything."

Hold your mind open to the possibility that your injury happened to help put you in the right place at the right time to align with your true destiny. While Kevin and Jill continue to add to and revise their someday list, they hope you'll start your own!

*James Bosch was burn injured as an infant. He has dedicated much of his professional life to the service of helping other burn survivors and their families heal and find meaning after a burn. Acceptance of new life, new body, and finding new meaning are at the core of his work. He is a member of the Phoenix Society for Burn Survivors SOAR National Advisory Committee and a consultant. James is a licensed psychotherapist in San Francisco, CA. ■*

# Lasers for Burn and Trauma Scar Rehabilitation: Giving Humans the Power to Heal by Themselves

By Jill S. Waibel, MD

Dermatology has been at the forefront of laser invention and innovation in medicine. One such innovation has been the “fractionation” of laser beams. These fractional lasers have now become an impressive tool in treating burn scars. Laser treatment of scars represents a major innovation that heals in ways not previously possible.

## A Breakthrough in Laser Science Leads to New Treatment

“Fractional” photothermolysis (laser resurfacing) has been the most remarkable breakthrough in clinical laser science since the development of “selective” photothermolysis, which enabled lasers to be used to treat targeted areas, while sparing the surrounding tissue. Fractional lasers create incredibly small, microscopic scars that the human body can heal quickly, allowing “remodeling” of the scarred skin layers to a more normal appearance. This method of skin resurfacing using a laser has led to clinical efficacy, or effectiveness, in aesthetic (cosmetic) procedures and scar treatment, with high physician and patient satisfaction.

This ability to remodel scarred skin via laser therapy is yielding results not previously possible. The human body can heal the smallest wound ever encountered (fractional wound) in scar tissue and the healing results in (almost) normal skin. In fact in 2013 *JAMA Dermatology* published a Consensus Statement entitled Laser Treatment of Traumatic Scars with an Emphasis on Ablative Fractional Laser Resurfacing, which concluded that scar treatment paradigms, or models, should include extensive integration of fractional resurfacing.

While reconstructive efforts can be limited by the development and persistence of pathologic scar formation, the best possible outcome for a patient who has experienced a significant injury can be achieved by coordinating the restoration of form and function. Both military and civilian research has revealed that fractional lasers can lead to both functional and cosmetic improvement. For example, patients often report improved range of motion with decreased pain and itching after one treatment. It also has been observed that scars continue to improve with each laser session. Given these results, the largest consumer market for lasers could potentially be in the treatment of scars.

## How It Works: Fractional Laser Physics for Scars

Research over the last 10 years has improved our understanding of the clinical effects, histologic changes, molecular cascades, and minimal risks associated with fractional laser resurfacing.

Fractional laser technology was introduced into our “tool kit” as a unique concept to create a pattern of hundreds of microscopic thermal injuries to skin. Again, the purpose of creating this pattern is that it stimulates and allows the human body to create a more rapid healing, a type of healing and pattern of injury that allows for that “remodeling” of the scar tissue to a more normal appearance.

The mechanism of action for ablative fractional therapy is complex. With temperatures reaching more than 100°C (212°F), the treated areas of the epidermis and dermis are vaporized, or ablated. In essence, ablative fractional lasers create microscopic full-thickness wounds. Immediately after ablation, damaged epithelia is eliminated and the excessive build-up of collagen fibers in the scar tissue shrinks. (The thickness and amount of collagen present in scar tissue can affect the appearance of scars.) Over the next 3 to 6 months, new collagen, the fibrous structural protein found in connective tissue under the skin layer, forms. The series of wounds that are created lead to newly synthesized collagen and granulation tissue, then eventual regeneration of the epidermis. Repeated treatments have continued effects with the greatest being on collagen formation—the new collagen forms in thinner bundles with this treatment, thus scar tissue shrinks and has a smoother appearance.

## Lasers and Surgery: Synergy for the Treatment of Scars

The treatment of scars is a multispecialty endeavor. A combination approach by medical experts yields optimal scar improvements. If an injury heals in the presence of tension, hypertrophy often ensues. This condition is characterized by deposits of excessive amounts of collagen, as previously explained, giving rise to a raised scar. Understanding the role of tension in the development of a scar is essential to designing a successful treatment strategy. If there is significant hypertrophy or contracture present in a scar, surgical

intervention is necessary to relieve the tension or there is a high likelihood the scar will reform. After tension relief, hypertrophic and contracture scars are more elastic with new remodeling of collagen and are more amenable to treatment with laser. However, if a scar has had initial fractional laser therapy this often makes surgical intervention easier to perform because the fractional laser therapy helps to create thinner collagen bundles.

### Laser Therapy for Burn and Traumatic Scars

**Erythematous scars** (reddened scars caused by a dilation of superficial blood vessels in the skin, or erythema), and **hypertrophic scars** (scars with excessive deposits of collagen that cause a raised-scar appearance) are seen frequently in the first year after injury. Vascular-specific lasers and light devices, especially the 595-nm pulsed dye laser (PDL), are already well established for such applications. PDL is often combined with fractional laser therapy—either in the same treatment session or in alternating sessions.

**Hypertrophic burn and traumatic scars** are best improved by ablative fractional lasers. Ablative lasers, when compared to other lasers, have a significantly greater potential depth of thermal injury. One such laser modified for the treatment of scars reaches 4.0 mm in depth. Furthermore, tissue ablation appears to induce a modest immediate photomechanical release of tension in some restrictive scars. An appropriate degree of surrounding thermal coagulation appears to facilitate the subsequent remodeling response. To determine the appropriate laser pulse energy settings (treatment depth), scar pliability and thickness is estimated by the physician through palpation, or physical exam by touch.

**Pigment-related abnormalities of scars** (hypopigmentation, or a lack of coloring; hyperpigmentation, or darkening; and depigmentation, a loss of pigment) can also be improved with fractional therapy. Flat or atrophic scars from burns and trauma also respond well to fractional laser therapy. Atrophic scars are dermal depressions that occur due to collagen destruction during an injury. The goal of laser treatment for atrophic scars is to stimulate collagen production within the atrophic areas. Neocollagenesis, or collagen production, is most stimulated by fractional laser therapy, making it the best choice for flat or thin scars.

### Fractional Laser Treatment: What to Expect

Any part of the body may potentially be treated with fractional laser therapy. The majority of fractional laser treatments can be performed in the clinic setting using a commercially available topical cream anesthetic preparation, which is applied under occlusion, or covered, 1 hour prior to treatment. Some patients may benefit from systemic preoperative analgesics (pain medication) or anxiolytics (anxiety medication). Conscious sedation or even general anesthesia can be employed in instances



**Triplets before and after a series of laser treatments. Today 2 of the women are married, and all have completed higher education and gone on to lead happy, productive lives.**

of large surface area involvement or anticipated poor patient tolerance of the procedure while awake. This is a particularly important consideration in children, as multiple treatments are usually required and children do not tolerate repeated painful interventions well. Patients experience minimal to no postoperative pain and little post-procedure downtime, resuming most normal activities after 48 hours.

With previous discussion in mind, fractional laser treatment technique, parameters, and adjunctive treatments should be applied thoughtfully to minimize the degree of cumulative thermal injury to the tissue. Each treatment is customized at every session according to individual scar characteristics and interval changes.

### Lasers for Mature Scars

Fractional lasers are not only effective on new scars. Mature scars, whether 1 or 60 years old, all respond well to laser therapy. For the past decade we have treated scars of all ages. A minimum treatment interval of 2 to 3 months between fractional laser treatments is recommended to give the compromised scar tissue time to heal. Even after just 1 treatment session, a patient may continue to have improvement for many months up to 1 year.

Problems associated with mature scars include burning, itching, pain, discomfort, disfigurement, contracture, and

limits to form and function. Fractional laser treatments have been successful not only in the appearance of scars but improving range of motion, while fractional ablative lasers also can have dramatic improvement in pain, itching, and burning.

I am currently honored to be in the process of treating Kim Phuc, who suffered the ravages of war as a 9-year-old child when she was burned with napalm during the Vietnam War. Her main complaint had been pain in her shoulder, where the fire bomb landed. Kim is now receiving laser treatments to reduce the damage to her body caused by the massive burns she suffered.

### Lasers for New Scars – Intervene Early for Possible Prevention of Scars

Traditionally reconstructive efforts have been delayed until 1 year after injury, at which point many patients have formed hypertrophic scars and have significant decrease in range of motion. In fact, burn and traumatic scars worsen during the proliferation of wound healing between 3 and 7 months after injury. Early anecdotal evidence suggests that using fractional ablative laser in the early phases may improve wound healing and decrease hypertrophic scar formation. The discrete ablative columns likely have various wound-healing advantages, including novel laser photomicrodebridement, biofilm disruption, and stimulation of deep dermal cells. Fractional lasers in photo-aged (sun- or UV-damaged) and scarred skin have been shown to stimulate growth factor secretion, increase collagen production, and improve the cosmesis of skin, while producing negligible local trauma. This provides a unique opportunity in this patient population to improve short-term and long-term healing and has implications for all wound healing in medicine.

For the past 5 years in our office we have been treating patients with lasers after burn and trauma injuries within 3 months of injury. We have found that with early intervention fewer treatments are needed and that laser appears to have a powerful scar preventative effect. I am currently at the end of a 2-year clinical trial prospectively studying early intervention of fractional ablative CO<sub>2</sub> laser with 830-nm LED phototherapy for acute burn injuries. Early laser intervention, especially in children, seems to melt away the scars, and fewer treatment sessions are needed.

### Laser-Assisted Delivery of Drugs and Cells to Enhance Treatment

Laser-assisted delivery (LAD) is an evolving method using full-field ablative devices. Fractional ablative lasers first emerged in 2007 and provide a novel way to create a conduit, or “channel,” through multi-thick layers in the skin, including the stratum corneum, epidermal, and dermal layers, in a rapid, predictable, and controlled pattern. These channels serve as access points for drug delivery or cell delivery, such as stem cells or skin cellular



**A 2-year-old child, 3 months post burn injury, before and after 2 treatments with pulsed dye laser, intense pulsed light laser, and fractional ablative laser.**

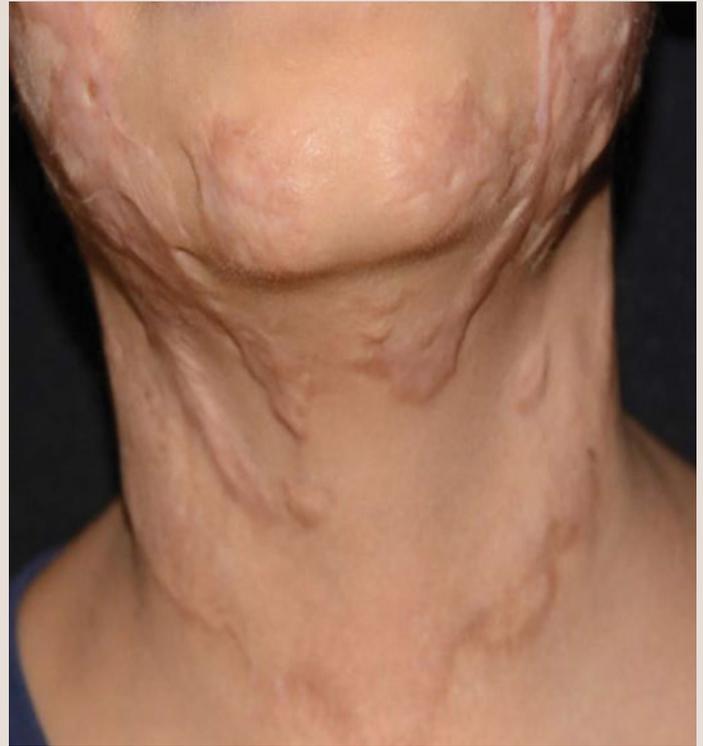
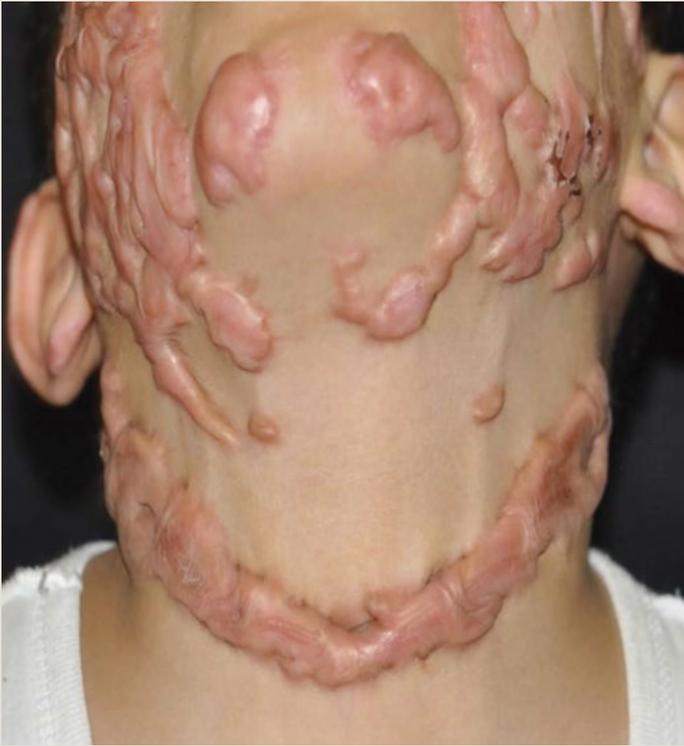
transplant, and allow for more effective transport of actives deeper into the skin.

LAD with ablative fractional laser pretreatment has already been reported and evaluated in clinical studies for a variety of dermatologic conditions. LAD of such actives as triamcinolone acetonide, 5-fluorouracil, poly-L-lactic acid, bimatoprost, PRP, vitamin CEF, biofilm, epidermal skin transplant, and stem cells for scars has been studied.

### Working Toward Insurance Reimbursement for Laser Resurfacing

One major drawback to laser resurfacing of scars is that no medical code exists for insurance reimbursement. As we have researched this issue, it has become clear that one of our responsibilities as physicians is to advocate for our patients and to work with American Medical Association’s coding committee, Tricare (the provider of civilian health benefits for military personnel, retirees, and dependents), and Congress to get such codes in place. It takes time, effort, science and a lot of work to bring a code to existence.

To achieve that goal, a group of veterans, philanthropists, physicians, and politicians have formed a nonprofit foundation, Restoring Heroes, that will develop, implement, and integrate a regimen (a protocol of care and treatment) for burns and scar trauma within the Department of Defense and Veterans Administration



**Before and after LAD with fractional ablative laser and triamcinolone acetoneide.**

healthcare systems for wounded, ill, and injured active duty and retired service members and their families, and veterans. The foundation will also work with Tricare, Congress, and the AMA/RUC (Specialty Society Relative Value Scale Update Committee) to establish additional codes to use laser and other cutting-edge modalities in the treatment of burn and trauma patients.

### Summary

Since their introduction, fractional lasers have helped many adults and children who have scar deformities. Patients and their families are grateful for these medical

devices. Personally it is very rewarding to be a physician who is part of improving a scar, regardless of whether the patient is an infant or an adult. The medical success of fractional lasers has added greatly to our ability as physicians to help heal our burn and trauma patients.

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# My Experience With Laser Treatments on Burn and Graft Scars

By Kris Flaten, M Div

Like so many of us who have had major body burns and grafts, I have scars, patterned with swirls, overlaid with diamonds of mesh, colored from deep red to white with edges hard and rough. Yes, I could accept them, grateful for life, but I wanted better. I wanted to be more comfortable. I wanted them to be softer, to have more movement, to be lighter in weight and color. Discouraged, I went to one last appointment, prepared to hear that there really weren't any acceptable options. That outlook

shifted when a physician's assistant entered the room and said, "I wonder if laser treatments would help."

Of course there were consultations, questions about insurance, as well as scheduling and transportation challenges. And I had questions about whether it would be worth it, how much pain there would be, whether I'd need to continue with compression garments, what kinds of risks were involved.

My burn sites were quite large—2 square feet of donor tissue were harvested for the grafts. They estimated I'd need 5 to 6 treatments for each of 4 areas of my body. I did the math and made a 1-year commitment to the process, which I started about 18 months ago.

The first treatment produced amazing results and each subsequent treatment has furthered that improvement. I am so incredibly grateful!

Don't get me wrong—I will still have scars, very noticeable scars. But now instead of being tough like elephant hide, they're much more like human skin. Now they stretch and move more easily and comfortably. Now both their coloring and weight are lighter.

It hasn't all been easy—emotionally or physically. The treatments can be quite painful, sometimes like getting 4 or 5 bee stings in the same place and then 4 or 5 more just next to those, over and over across the scar. That pain doesn't last long but it can be intense. It's also not predictable; usually I don't feel much through the grafts, but sometimes I do. The edges of the scars can be really sensitive. We've worked at and refined a pain management system: A couple of hours before the treatment I slather on a lidocaine/prilocaine prescription cream (EMLA) and then cover it with plastic wrap. About 20 minutes before the treatment, (usually in the parking lot) I take a pain pill. After the treatment, I may take another, but it's usually not needed.

During the procedure, I wear goggles to protect my eyes. I am also given a hose to blow cold air on the site just after the lasering, which numbs the tissues and lessens the pain. After the treatment is completed, a steroid solution



**Before laser treatment**



**After 4-5 laser treatments**

is wiped on. That can itch, even hurt a little. It needs to soak in for 3-4 hours so it's covered with a Tegaderm dressing. Then comes the messy part: blood and fluids ooze for several hours. Then the new "wounds" close (usually without scabs). For the next few days, the area is a little swollen and more red, sometimes a little sore and/or itchy. Moisturizing is important—both for comfort and healing. The skin has to heal for 2 months before

it can be treated again. I have experienced some fatigue with the treatments so I have learned that I need extra rest while my skin is healing.

The emotional part in some ways has been more difficult for me. During the treatment, I'm in the same physical position I was often in during hydrotherapy in the hospital, so those memories did come flooding back pretty intensely, especially at first. To help with my anxiety, I took lots of deep breaths and reassured myself a lot.

Often I smell the skin burning, particularly when the treatments are on my upper chest. We also end up blowing the tiny skin fragments off my face, similar to getting hair blown off after a haircut. The messy part has taken me back to those first months of daily wound care and the pain, itching, and fears associated with that. To be honest, after the first treatment I wasn't sure I'd continue. But I've found that going through these treatments has actually been healing to those memories; with these treatments the experience is not as intense and it doesn't last as long so my body is learning to expect an easier experience than the ones I had had in the hospital. And, as I've said, the benefits to my skin (and self-esteem) are really worth it!

Here's my advice to others undergoing laser treatments:

- Ask lots of questions. There are many kinds of lasers, which can be set at different depths for different numbers of passes or overlaps. Some are faster than others. Be curious.
- Tell people what the treatments are like for you.
- Problem-solve with your providers, family, and/or support system on how to make the treatments more comfortable and easier for you to tolerate. We are each different!
- Reward yourself after each treatment. (I often had a book I had looked forward to reading, or I would take myself out to a movie or lunch.)
- Ask for what you need. After the full treatment it was difficult for me to do the first dressing myself and get it on securely so I asked if I could come back (3-4 hours later, after the steroid had had time to soak in) and get some help with it. The medical staff was happy to work that in and doing so worked well for me. I left the dressing on for 24 hours, after which I was able to change it myself.
- Be gentle with yourself. I usually don't plan anything else for the day I am being treated, then I'll do things as I feel up to them.
- Enjoy the results; encourage yourself and your skin.

*Kris Flaten, M Div, of St. Paul, Minnesota, sustained a thermal burn injury on Dec. 25, 2012. ■*



## Life Transitions, Part 1

# Becoming a Leader

By Jess Irven, MS, LRT/CTRS, CCLS

Navigating transitions and change is the very essence of life. As we move through different seasons of the year, ages, relationships, and jobs and all that they bring, change is inevitable. How we approach, navigate, and react to these transitions shapes not only who we are, but also our future.

Some changes and transitions are expected, welcome, even eagerly anticipated. The unexpected also happens, though; life can change in an instant without warning. Such is the case with trauma and injury. Yet this article is not about how burn survivors react to the physical transitions introduced by an injury (for example, medical care, changed appearance, and possibly changed abilities), but how burn survivors approach and navigate other “life” transitions following their injuries.

Why does this matter? How could burn injury affect your experiences during these life transitions? A burn injury can have an impact on how you approach change. You may feel that because you have faced “the worst” (that is, a burn injury) and come through as a survivor, you can handle anything, or you may feel limited by and possibly even fearful of even the smallest changes (especially when unknown).

In this, the first article in a 2-part series, we will look at the transitions inherent of personal growth within the burn camp and other support programs. In our next issue we’ll examine how young adult burn survivors face the transition from high school to whatever comes next.

## Burn Camp Provides a Navigable Path

The supportive structure of the burn camp world provides a known and navigable path on which you can expect, practice, and process through transitions. Progressing from camper to counselor in training, or CIT, to counselor allows you to be mentored into responsibility. It provides opportunities for you to serve younger campers and to practice leadership skills.

Experiences for a CIT (sometimes called an LIT, or leader in training) often include sharing your personal burn survivor story, as well as leading by example as a burn survivor who copes well with post-burn injury life. It also brings carefully planned mentor opportunities from camp staff and fellow volunteers, affording leadership skills, accountability for actions, and empowerment to employ these skills in a new role. With the next step a clear one (becoming a counselor and adult leader within the camp structure, and an adult burn survivor who gives back to the community), the path of transitions within the burn camp world is clear and supportive. Many camps and support programs also offer teen-specific programming, or even a separate teen camp, during the year for further support.

Kendall Rowdy, a North Carolina teen burn survivor, saw the opportunity to be a CIT as the next step in his growth and healing process. "It gave me the chance to have a positive impact on someone who has been through the trauma of being burned and has survived like I have," says Kendall. He explains that he became a role model by using his own survivor story and sharing his own experiences "to let them [the campers] see and know that just because you've been burned doesn't mean that your life is over."

Describing the training and mentorship he benefited from, Kendall says, "CIT training prepared me in so many ways." There, he says, he was shown "all the ropes." He learned he could serve as a role model for kids who might be having difficulty coping with their burn injury and help them realize that they aren't different from other people.

"I'm very positive," says Kendall, "that I left a lasting impact on some campers." He describes using his skills to "keep watch over the campers" and to be supportive "in the moment." When he noticed that a camper was sad, homesick, not having fun with the activity, or just in need of someone to talk to, Kendall says he was able to be "a big brother." "Even if just for a couple of minutes," recalls Kendall, "it gave me the satisfaction of just being there for someone."

Positive feelings and skills, such as those described by the teen, infuse into a young survivor's identity and life at home. Research has shown that adolescents who attend burn camp experience far-reaching benefits, such as identity formation and communication.<sup>1</sup> "Camp gave

me a lot of things to go out and share with others," says Kendall. "It taught me to be who I am and that I'm not going to let one bad experience change who I am. It gave me better leadership skills."

Mentors also learn about the value of using their stories and their own healing journeys in ways that have a positive impact on others. In short, mentoring support programs help survivors, as well as inspire survivors to help others.

### **To get involved in a structured burn camp/mentorship experience**

- Contact the burn camps closest to you to ask about their programming for different age groups. To find camps for children and teen burn survivors, or to apply to volunteer, go the International Association of Burn Camps website, <http://www.iaburncamps.org/>.
- Ask about requirements to participate in teen programming.
- Ask about requirements to participate in leadership development programming (such as CIT programs). Some camps prefer that you attend one of their regular camps, teen camps, or other events prior to applying for a leadership program.
- Begin practicing accountability by completing the necessary steps for application on time and independently.

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*"It [being a CIT] gave me the chance to have a positive impact on someone who has been through the trauma of being burned and has survived like I have."*

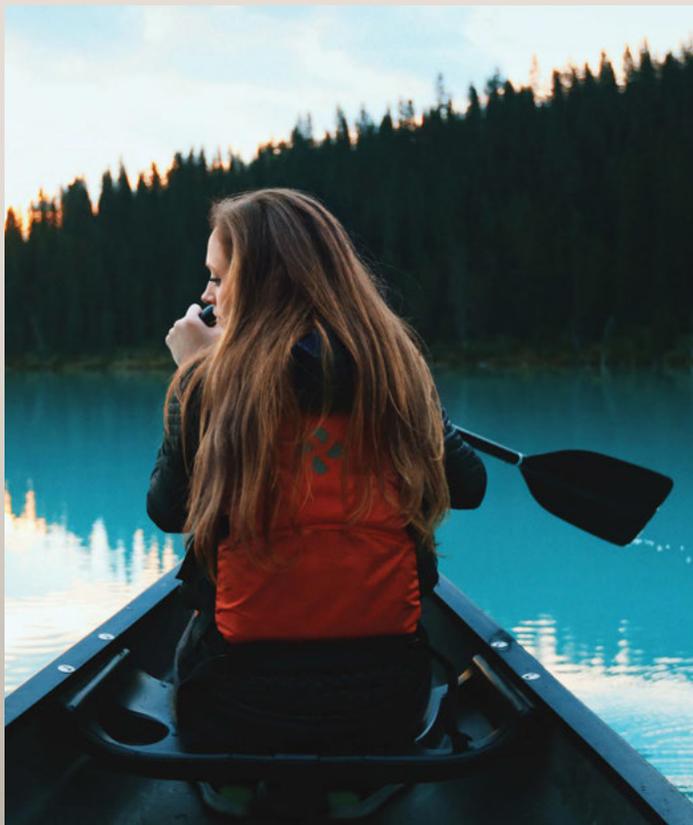
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## Phoenix UBelong and Young Adult Workshop Programs Provide Space for Growth

Camp leadership opportunities also open the door for young burn survivors to hone leadership skills that can be used in a wider burn survivor support arena, such as in the Phoenix UBelong Youth and Family Programming at the annual Phoenix World Burn Congress. Phoenix UBelong programming includes an evolving strategy for supporting teens through transitions. The program has been developed to address the needs of emerging teen leaders and empower them within the program structure.

In UBelong Youth and Teens, the program for 7- to 17-years-old, teens have the opportunity to interact with the younger participants. In UBelong Young Adult, the program for 18- to 25-year-olds, selected young adults have the opportunity to serve as mentors to their peers, gaining workshop planning and peer support knowledge as they assist the workshop facilitators. These Young Adult mentors, who apply for these positions in advance, are an integral part of the facilitation team and offer their personal survivor stories of thriving after burn injury as part of their lead-by-example service. Clearly the previous experiences gained in a burn camp setting have value in this setting, as evidenced by the fact that all Young Adult mentors who have participated thus far have brought with them knowledge and experience learned from participating in support experiences at their local burn camps.

Branden Winters is one example of a young burn survivor who gained such skills in the camp environment and then further deepened his experiences at a broader support programming level as a mentor in the UBelong Young Adult Workshop. Branden, who had served as an LIT at BUCKO, Burn Camp for Kids in Ontario, says, "There are so many people that have had to go through obstacles and endure similar situations as myself. . . I truly didn't think I could make a difference in someone's life." However, he explains, that by being a leader and helping other survivors through Camp BUCKO and Phoenix Young Adult Workshop, he has learned, grown, and even gained a sense of direction. "This experience has opened my eyes to the future of the burn community



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*The supportive structure of the burn camp world provides a known and navigable path on which you can expect, practice, and process through transitions.*

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and more opportunities to help others," says the UBelong Young Adult mentor, explaining that for a long time he had been seeking an opportunity to be more involved and that he now he hopes to one day "be invested full time in such an area."

Branden looks back at his role in UBelong Youth and Teen with sincere appreciation. "Many years ago, someone said to my mom, 'Good things will come out of this tragedy,' and this week is pure evidence. I would not change what has happened to me or I would have never gotten the opportunity to experience what I experienced this week," he explains. "For that, words do not express the gratitude I have for this wonderful opportunity."

***To take the next step in leadership and become involved in UBelong Young Adult programming, you should***

- Apply online to be a UBelong Young Adult mentor, keeping in mind the following guidelines:
  - You must be at least age 18/out of high school and no older than 25.
  - Mentors are selected following an application and interview process, therefore you should thoughtfully construct your application content.
  - Applications open in early April and close in May.
  - Mentors can apply for Phoenix WBC scholarship funds on an as-needed basis to support attendance and travel.
- Strongly consider attending the UBelong Young Adult Workshop even if you are not a mentor; learning the techniques and understanding the role by watching current mentors will help strengthen your knowledge and ability to demonstrate how you can add your own skills to the programming next year.
- Visit <http://www.phoenix-society.org/wbc/phoenix-ubelong> for more information about UBelong Youth and Teens, and UBelong Young Adult Workshop, including the mentor role. (Applications to serve as a Young Adult Mentor may be submitted beginning in April each year.) ■

***Reference***

1. Rimmer RB, Pressman MS, Takach OP, et al. Burn-injured adolescents report gaining multiple developmental benefits and improved life skills as a result of burn camp attendance. *J Burn Care Res.* 2012;33:552-560. doi: 10.1097/BCR.0b013e318242ef11.

# Hidden Burns Matter

By Mikki Rothbauer, MSW, LICSW

As I reflect about hidden burns and the challenges they pose for survivors, I must acknowledge the countless survivors who have openly shared their thoughts and emotions about this topic. I have seen pain and suffering from survivors and admire their strength and bravery as they address the complexity of healing emotionally from a hidden burn.

What is a hidden burn? This is a question someone outside the burn community may ask. A hidden burn is a burn that can be covered by clothing or isn't visible to the eye, such as a thermal or electrical burn. I would add that a hidden burn is hidden pain. This pain is real. This pain is justified.

As a burn care provider, I have seen a large spectrum of perspectives about hidden burns from patients, family members, and the community. For patients and families these perspectives can often change during the hospital course and post discharge. Often when patients are first admitted with hidden burns, they or their families make such comments as "We are just thankful it isn't on her face" or "At least I will be able to cover it up." These statements may be true but can be difficult to hear for a survivor who is feeling the physical and emotional pain of the injury and interprets this as dismissive. As survivors recover and heal, the burn is still a part of daily life.

One challenge that hidden burn survivors face is feeling that their experience is minimized by others because it



isn't visible. It is normal for survivors to wish they had a visible burn so what they are feeling and the struggles they may be having are out for the world to see. This isn't saying hidden burn survivors want sympathy, but acknowledging the burn is acknowledging the pain they've experienced and may still be experiencing. Feeling "visible burn envy" is okay. This may not make sense to anyone but you, and that too is okay.

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*...hidden burn is hidden pain.  
This pain is real. This pain is justified.*

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Intimacy is also a significant hurdle for hidden burn survivors. Those who are in a relationship at the time of the injury and others who are initiating a relationship post-injury are faced with the challenge of "showing" their burn. For some this is not an issue, but for others this is incredibly anxiety-provoking. Avoiding intimacy or even relationships can seem to be the easiest solution for some. My hope is that if you are struggling with this, you can reach out to your local burn support group, Phoenix Society chat room, or a Phoenix SOAR volunteer as I can assure you there are others who have been in the exact same place as you. There is not a "right" or "wrong" time to share this part of yourself. Your scars symbolize pain, strength, and survivorship.

Hidden burns can also mean that sharing is optional. You can choose if, when, where, and how you will share your story. This can be viewed as an advantage or a disadvantage. The advantage of it is that you are able to have some control in what can seem a powerless experience. You get to choose if you want to tell your story or to mention it in passing so as not to draw attention. In addition, there is more opportunity to choose with whom and when you want to talk about what happened. However, you may also avoid situations where you would have to show your burn, ignore the burn and all the emotions behind it for months or even years, and miss out on loving and respecting yourself and all you have to offer.

Hidden burn survivors face many challenges, but there are resources and tools available to you. Creating positive affirmations, writing them down, rehearsing them, and using them is one way. For example, "I am beautiful;

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continued on page 19

# With Your Support, We Can Bridge the Gap

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*"It can be lonely."*

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*Growing up over 100 miles from the nearest burn hospital and hours from survivors her own age, it has been hard for her not to feel alone...isolated...different.*

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"It can be lonely." For a 17-year-old burn survivor, the world can feel pretty small when you live in a remote little town.

Kelsay Parrott, of Cherokee, Iowa, was only 4 years old when a tiny spark strayed from a candle, found a string on her dress...and changed everything. Growing up over 100 miles from the nearest burn hospital and hours from survivors her own age, it has been hard for her not to feel alone...isolated...different.

Through the years, she has attended burn camps, visited hospitals, and gone to special events for burn survivors. At each, she met special people and was reminded that she's not alone.

But upon returning to the routines of rural life, her world would quickly shrink again. Connections would fade. And that sense of seclusion would sneak back in.

So when Kelsay decided to attend her first Phoenix World Burn Congress last fall, the teen hardly dared to



hope that things would be any different. But different can't even begin to describe her experience.

"It was life changing," recalls Kelsay. "There was this huge feeling of relief. I just knew that I was going to be okay."

For the first time in her life, the teenager found herself fully immersed in a culture that truly understood. Surrounded by an entire community of peers, there was a sense of belonging and total acceptance, unlike anything she'd ever known.

For those 4 days, Kelsay bonded with other teenage survivors in the Phoenix UBelong program. Instant connections turned into real friendships. Through the activities, the sessions, the dialogue, the camaraderie, she discovered a new level of support, confidence, and hope.

"We were really able to draw strength from each other," remarks Kelsay. "Being with so many different survivors with so many different stories, it changed my outlook on how I can get through the hard stuff in life."

Kelsay was afraid that leaving her newfound burn family was going to be hard. Going home, she knew, would place miles and hours between them. And distance had always meant loneliness for Kelsay. But not this time.

This time there was an unbreakable link, in the form of technology—a digital bridge that closed that gap, joining her to the community she had found at Phoenix WBC.



Kelsay with her mother, Michelle

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*"Since the conference, I've been able to stay connected through the Phoenix Society's online programs and services that I didn't know about before," says Kelsay.*

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"Since the conference, I've been able to stay connected through the Phoenix Society's online programs and services that I didn't know about before," says Kelsay.

Phoenix Society's online peer support chat, blogs, survivor stories—they keep her close and connected. The support and relationships infuse her with energy and encouragement. They empower her to reach out for help when she needs it. And inspire her to give back in every way that she can.

"Where I live, it was always hard for me to find and connect with other survivors," explains Kelsay. "Phoenix Society and Phoenix World Burn Congress have opened my world."

Kelsay was never alone. And now, with an entire community at her fingertips, she knows it.



Kelsay with her Phoenix UBelong friends

***Your dollars open worlds. Thanks to donors like you, the Phoenix Society is continually advancing technology to reach more survivors, such as Kelsay. With your continued support, we won't stop until every survivor knows they are never alone.***

***Make your gift today online at [www.phoenix-society.org/donate](http://www.phoenix-society.org/donate) or use the convenient envelope provided in this issue.***

# Guilt...

## One Way That We Cope

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Jennifer Harris, LICSW

Of all the emotions that families endure in a crisis, guilt seems to be one of the hardest to resolve. Guilt is a feeling or a thought in which you have or perceive that you have harmed or wronged someone. In many circumstances, guilt comes on as a result of doing something to someone that requires his or her forgiveness in order to heal. However, in the instance of family coping with a loved one's burn recovery, the guilt that one can experience is often a result of burdensome thoughts we place on ourselves. It is what I call the "coulda, shoulda, woulda" effect. It is the magical thinking that helps return to us some control of a situation that is out of our control.

When I work with families on the burn unit, I always hear such comments as "If only I had done...," "I should have...," "I wish I could have... ." While the rational part of us knows we cannot go back to change events, the compassion and loving side of us holds on to the guilt. It is part of how we cope with making sense of what has happened. While some guilt is helpful to motivate us to positive action to care for our loved one, unjustified guilt can become overwhelming and interfere with well-being.

So, who experiences guilt? Anyone—parents, siblings (old and young), spouses, extended family, witnesses of

the event—anyone! Guilt is part of the healing process. It is perhaps how our thoughts and emotions try to gain control when we have been thrust into a trauma that has taken away much of our control. But the guilt we experience is often not just related to the burn event itself; it also comes and goes during our loved one's recovery.

Anyone in a family may experience feelings and thoughts of guilt, including

- Survivor guilt (your loved one was injured and you were not)
- Guilt that you can't visit more/spend time with or support your loved ones as much as you would like
- Guilt that you are not visiting because doing so makes you anxious
- Guilt that you are jealous that you are not getting as much attention as before
- Guilt that you resent how life has changed as a result of the injury
- Guilt that your loved one is being stared at or treated differently in public



- The worry or guilt of a child who thinks they did something to cause the injury and/or could have done something to prevent it

Does any of this sound or feel familiar? If so, do not worry. Anyone can have thoughts or feelings of guilt. It is how we make sense of what is going on with a disruption in our life. But if guilt takes over and keeps you from engaging in the life that you deserve, that is cause for concern.

While you may know that *you* are having these feelings and thoughts, how will you know if someone else in the family is too? Look out for symptoms and behaviors such as these:

- Anxiety/depression
- Loss of interest in friends or favorite activities
- Increased irritability or anger
- Poor performance in school or work
- Decreased ability to focus
- Acting out or being rebellious
- Use of substances or increase in alcohol intake
- Intrusive thoughts or behaviors to control a situation

Of course, it's important to know that there may be other symptoms or behaviors that could be added to this list and to realize that not everyone will have noticeable behaviors. You should also keep in mind that these behaviors are a means of coping with intense feelings or thoughts of guilt. However, if they are not helpful in the healing process, it's important to consider seeking help before these behaviors put someone's well-being at risk. That negative effect on well-being will become noticeable when the completion of normal or everyday activities becomes hindered on a regular bases.

Many families ask how they can avoid the use of disruptive coping mechanisms. I suggest they validate the thoughts and feelings that members of their family are having. While reading this article, have you felt a slight sense of relief from knowing that you are not alone in your experience of grief, or even just learning that guilt is a normal process of coping with trauma? If so, that is because you experienced validation. Having a safe space to share your thoughts and feelings is crucial to experience validation. Everyone needs a safe space to share their thoughts and feelings of guilt. You can provide this to your family simply by creating a space to just listen, without using judgmental language. If it feels

too intense to create or maintain this space, then you might consult with the burn team about enlisting the support of a mental health clinician.

In addition to validation, there are some other healthy coping strategies that can help families deal with guilt:

- Maintain normalcy and routine (as much as possible) at home, particularly when children or teens are involved as it allows them to have alone time with you.
- Provide honest and accurate information about the injury.
- Sustain positive self-talk or self-affirmations.
- Stay connected with family, friends, spiritual community, and school.
- Keep a journal or write reflections of positive things or things for which you are grateful
- If talking becomes overwhelming, keep a family dialogue book, where everyone can share their feelings without the intensity of having to talk about it.
- Remember that your loved one most likely does not blame you for what they are going through, and if you asked, they would probably tell you as much.

Finally, and probably most importantly, give yourself permission to take care of yourself. You have experienced this trauma too. Incorporating a regular schedule of self-care will give you a space to clear your mind and rejuvenate. We know that including a few minutes to be present in the moment allows our thoughts and feelings

to be less intense and heal. I know, that's easier said than done, and possibly feels like it might create more guilt that you are being selfish. But you will not be able support your loved one if you do not take care of yourself. Think about incorporating a few minutes a day, every other day or even weekly, of some activity that you identify as self-care. It does not have to be an elaborate experience, such as a massage or facial. It could be as simple as talking a walk, getting coffee with a friend, coloring, cooking a nice meal, meditating, or another activity that helps create a space to be present and reboot.

Combating the "coulda, shoulda, woulda" effect of coping with trauma is not easy and takes some work. The propensity to allow the magical thinking of guilt to creep into our coping and consume us is strong. But, you *do* have the tools in your coping "toolbelt" to help ease the intensity of guilt so that you can begin to heal from this traumatic event. The key is to utilize those tools in any capacity to keep from dwelling on the things that are out of your control. Guilt may feel inevitable, but having space in your life and your family for self-care, validation, normalcy, and community will support you in your healing.

*Jennifer Harris, LICSW, is a clinical social worker who previously worked at Massachusetts General Hospital Burn and Reconstructive Plastics Services in Boston, Massachusetts. She has recently transitioned to private practice and remains involved with the Phoenix Society for Burn Survivors. ■*



**Phoenix Society**  
for burn survivors

PEG Scholarship

## Don't Miss This Opportunity!

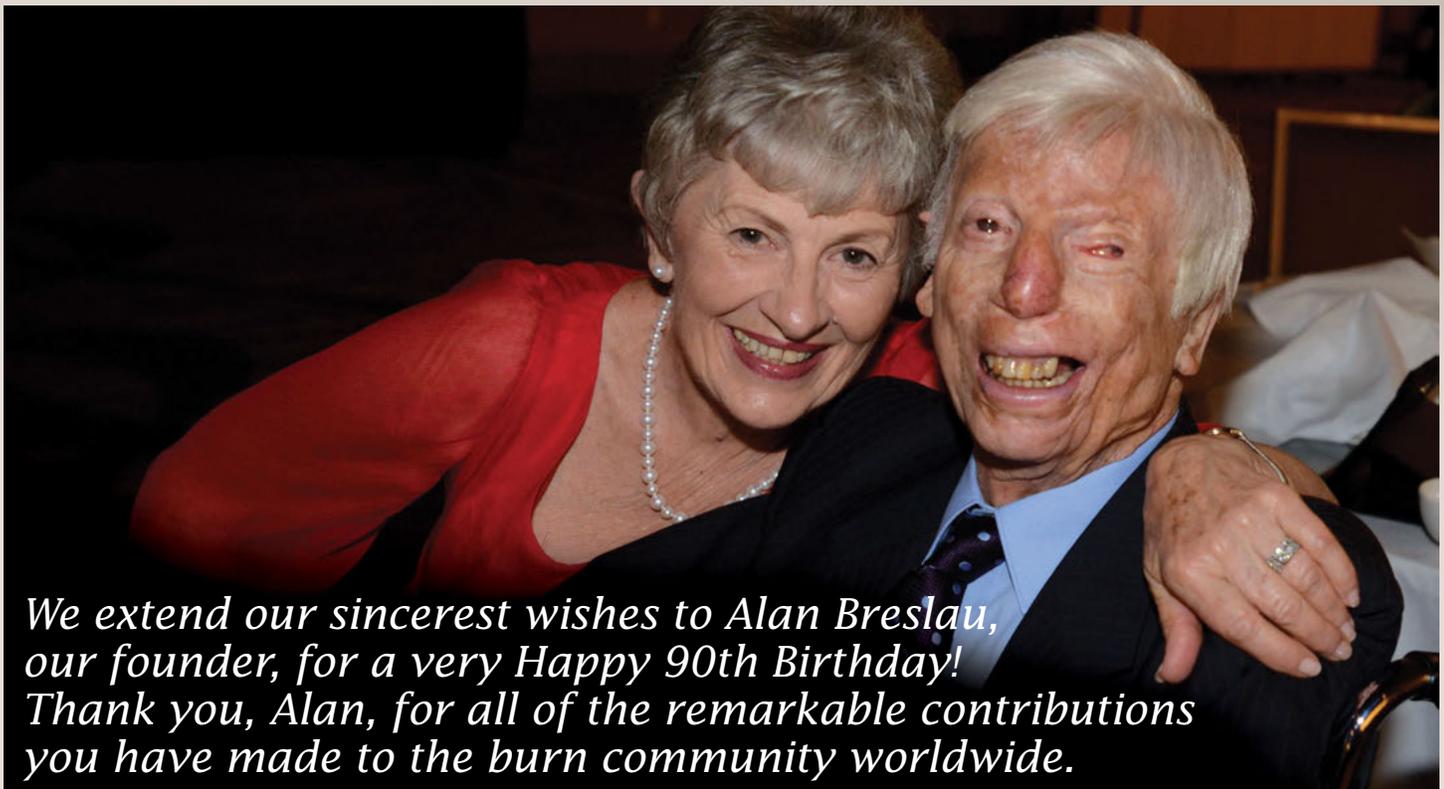
## PEG Scholarship Applications Due July 1

Each year the Phoenix Society awards several scholarships to burn survivors who are attending college or technical school. The program to date has issued a total of 146. To learn more about this scholarship program and download an application, visit [www.phoenix-society.org/peg/](http://www.phoenix-society.org/peg/). Completed applications and all supporting documentation for the 2016 Phoenix Education Grants must be submitted no later than July 1, 2016.

All monetary awards are made possible by contributions to the PEG endowment fund. If you would like to help other burn survivors continue their education, please make a contribution to the PEG fund at [www.phoenix-society.org/peg/](http://www.phoenix-society.org/peg/).

*PEG is made possible by generous gifts from individuals and by a generous 10-year pledge of \$25,000 per year from our partner, AlloSource.*





*We extend our sincerest wishes to Alan Breslau, our founder, for a very Happy 90th Birthday! Thank you, Alan, for all of the remarkable contributions you have made to the burn community worldwide.*

## Seeking Nominations for the 2016 Breslau Award

The Alan and Delwyn Breslau Award is presented to an individual who has, through a collaborative spirit, significantly enhanced the ability of the Phoenix Society to fulfill its mission of peer support, education, collaboration, and advocacy.

To nominate an individual, submit your name and address, as well as your nominee's contact information, a letter detailing why your nominee should be selected, and any other relevant information no later than July 1, 2016, by email to [andrea@phoenix-society.org](mailto:andrea@phoenix-society.org). The 2016 Breslau Award will be presented at Phoenix World Burn Congress this fall.

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### continued from page 13

my skin represents healing and strength and my loving friendships represent my kind spirit." Practicing the way you would share your story prior to doing so can decrease your anxiety in that moment of vulnerability. In addition, you can find resources, chats, and forums at [www.phoenix-society.com](http://www.phoenix-society.com).

At the 2015 Phoenix World Burn Congress, many brave individuals met to share what has been difficult and what has been helpful about the experience of a hidden burn. In addition to survivors, there were significant others, parents, grandparents, children, and friends of survivors sharing their experiences. There is a sense of gratitude for surviving and being able to talk openly about this subject. Knowing that there are others who have walked a similar path that you are walking makes that lonely path feel less quiet. For many, it was the first time they heard someone share the idea of wishing for a visible burn. It also was a safe place for those who admittedly keep their burns covered because they aren't ready to share them with anyone. Those of you who have been on this journey know that it is not an easy one, and not

without bumps and obstacles, but you also have shown resilience, strength, and hope to others in sharing of yourselves and listening to others.

In closing, if you are, or you know and love someone who is, a burn survivor with a hidden burn, I want you to know that

- You and your experiences are valid.
- Your stories are worth telling.
- Your pain is real.
- Your perspective matters.
- Your scars represent survival and strength.

*Mikki Rothbauer is a social worker and psychotherapist at Regions Hospital Burn Center in St. Paul, Minnesota. She has been providing psychological care in the burn community for more than 12 years. She is an active member of the American Burn Association and a strong supporter of the Phoenix Society. ■*

# Right Where We Want to Be

By Rebekah Reishus Allely,  
OTR/L

*Rebekah Reishus Allely earned a BA in mental health/human services from Franciscan University and a BS in occupational therapy from Eastern Michigan University. Rebekah has worked at MedStar Washington Hospital Center as a burn rehab therapist for more than 25 years.*



There are many health professionals who stumble into the world of burns, but those of us who choose to stay year after year have found that it is our passion. There is a sense that this is where we were meant to be.

## **Facing Challenges Together**

The journey of recovery from a burn injury is long, slow, and multifaceted. Our patients' challenges are diverse, and perhaps that is one of the aspects we love about being a therapist on a burn unit. A day's work finds us engaged in our patients' physical and emotional challenges. While there are similarities from one patient to the next, each one's story and the challenges he or she face are unique to that individual.

As burn therapists, we have the privilege of walking alongside our patients as they face the difficult work of recovery. The scope of their issues is wide, the list of their challenges is long. Our patients deal with the pain of open wounds, the painful stretching of skin, the loss of independence, the fear of not knowing what lies ahead, the questioning of why this happened, the changes in body image, the feeling of being a victim, the change in their roles within the family, and the process of acceptance. They wonder how their loved ones will deal with their injury. They work hard to regain motion, strength, and independence and deal with the acceptance of scar. Being overwhelmed is completely understandable!

As therapists, we also have the challenge of developing a relationship in which we can lead patients through painful exercises, convince them to sleep in positions that are not comfortable and wear splints and pressure garments that are unpleasant, and let us massage skin that hurts. We ask them to walk when they have little strength, feed themselves when they'd rather be fed—all while they are looking at their skin and thinking that this is not what they want to look like.

The therapist-patient relationship can be our greatest challenge and our greatest joy. It is incredibly frustrating when we are unable to motivate patients and they are unable to engage in their own recovery. Likewise, it makes our day when we work with patients through painful exercises and see them steadily make gains toward independence.

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*The therapist-patient relationship can be our greatest challenge and our greatest joy.*

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### Learning From Our Patients

We also learn so much from our patients. Once when talking with a burn survivor at Phoenix World Burn Congress I asked what advice she had for me as a burn therapist. This woman emphatically looked at me and said, "Don't ever, ever give up on a patient!" She went on to tell her story of how noncompliant she was with her rehab, how depressed she became in the midst of her recovery, and how her world seemed completely dark. But eventually, she said, she found her way forward and is now so happy to be one who survived and is living a happy, meaningful life. I will never forget her words to me.

### Being Part of a Team

I have been fortunate to work with an amazing team of health professionals at MedStar Washington Hospital Center, as well as with a dedicated group of firefighters in the DC Firefighter Burn Foundation. Through the generosity of the Burn Foundation and the support of MedStar we have partnered with the Phoenix Society to provide Phoenix SOAR peer support for our patients and image enhancement for those with pigment differences. We have the privilege of taking a group of patients and

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*If I had to name an event that significantly changed my work as a burn therapist it would be, without question, the first time I attended Phoenix World Burn Congress.*

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burn staff to Phoenix World Burn Congress each year. If I had to name an event that significantly changed my work as a burn therapist it would be, without question, the first time I attended Phoenix World Burn Congress. My eyes were opened to the long-term struggles of burn survivors and their ability to persevere. I learned new skills to better support them in their recovery. I saw many people, who had been through so much, who were happy to have had the care they had received and are now enjoying life.

It was at Phoenix WBC in Galveston, Texas, that the DC Firefighters met the staff from the Adaptive Sports Center in Crested Butte, Colorado, and we began a partnership—taking patients for a week of outdoor adventure in Colorado. This experience of stepping outside one's comfort zone, being challenged both physically and mentally, has a profound ripple effect through a person's life. Our burn team has come to appreciate the importance of leisure and recreation in our patients' recovery. Returning to work is very valuable, but returning to the enjoyment of recreational activities is life-giving.

This is the beauty of being a burn therapist—we're a member of a team who works incredibly hard to help people recover from the burn injuries that turned their lives upside down. We have the gift of making a difference in people's lives and to learn from our patients' strength and courage. This team we're part of begins with our own burn units and fire departments, extends across the United States, and to countries as far away as Bangladesh. We're part of a greater burn community that comprises health professionals, firefighters, burn survivors, the adaptive sports world, the Phoenix Society, and many, many supporters.

There really is nowhere else I would want to be. ■

## Rebecca's Advice to Patients

- Don't hesitate to be honest with your therapist about what's working well for you and what's not.
- If you can't tolerate a compression garment or a splint, talk about it so you can make adjustments or compromise on a wearing schedule.
- If you're having trouble with your home exercise plan, let your therapist know—we will work with you to solve problems and make adjustments to improve your ability to exercise and meet your rehab goals.



# What Matters Most

By Amy Acton, RN, BSN  
Executive Director

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“Our human compassion binds us the one to the other – not in pity or patronizingly but as human beings who have learnt how to turn our common suffering into hope for the future.”

— Nelson Mandela

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As I reflect on the last couple weeks and grieve one of the toughest losses one can experience, the loss of the person who brought me into this world, my dear sweet courageous mother, Pat—my closest friend, confidant, travel buddy, my children’s grandma, my rock—I cannot help but go back to a time when I needed her the most. Thirty-five years ago I woke in the burn center to find my mother standing at my bedside, where she remained for the next 79 days, and the rest of her life—with love, compassion, and hope in her eyes. That time of trauma deepened what was already present in my relationship with my mother and with the rest of my family—love and acceptance. While at age 18 I hadn’t yet recognized the significance of the profound gift that they were in my life, I soon woke up to realize its importance. And now those overwhelming feelings of gratitude for that amazing gift of “family” have been rekindled with my mother’s death.

The pain and trials of our burn injury have a lasting impact on our relationships. Our “families,” whether they are our blood relatives, caregivers, or friends, remind us that we do not travel our road alone. I drew strength from these deep connections over the last several weeks as I coped with a different loss.

My family gathered to walk with my mom on the last days of her life’s journey. We spent the time at her side, sharing tears, laughter, and stories of our times together. It was here that I was again reduced to that very emotional raw, yet open, place that felt familiar to me. The feelings of absolute loss, helplessness, the unknown, and fear about the future that so many of us felt during our burn recovery. It is the same place where truth is spoken freely, love is given to soothe one another, and compassion is felt through a touch and a tear, where you want nothing left unsaid because you don’t know what

tomorrow will bring, where you have the desire to be fully and utterly present with each other.

I knew my mom was dying. She had been beating the odds for several years. She taught me during her illness that acceptance and living despite our limitations could be done with grace and gusto. She used to say “I have more I want to do.” Rather than focus on her own troubles and what she could not do, she went on and got the most out of each day. She shared with me in her last week that she was looking for something, a verse or something, to give her the strength she needed. Pat always looked for a quote or prayer that spoke to her during challenging times and when she was suffering. She had a few favorites she would share and read during the really tough patches when I was in the hospital. It buoyed my hopes then and it is now something I do in my own life when I need some added inspiration.

Unfortunately, I didn’t find out while she was still able to tell me if my mom had found that special verse or quote. But my hope is that the sound of her children laughing, crying, and living life around her in those final hours brought great comfort to her, that our words of comfort spoken in her ear helped her find peace and strength, because she has helped us all see during different times in our lives that, despite deep suffering, life can be full and lived even more deeply because of it. That letting the tears wash through us like a spring rain will leave behind what matters the most—each other. ■

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Staying vulnerable is a risk we have to take if we want to experience connection.

— Brené Brown

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## PHOENIX CHAMPIONS - MEMBERS OF THE PHOENIX SOCIETY MONTHLY GIVING CLUB

Megan Baldonado  
Meredith Balgley and Erik Bendix  
Deborah L. Bostic

Tod and Lisa Breslau  
Anthony F. Burke and Stacey Loen-Burke  
Sonia Castleberry

Linda Courtice  
Sonya Cromwell  
Rebecca Dowling  
Teresa Deninger

Janet Harman, RN  
Debra and Tom Jones  
Barbara Kanegis  
Siena Riffia

Anne Scholl  
Dr. Lynn and Pat Solem  
June Vaughn  
Tony Warnick  
Megan Yankee

## BENEFACTORS SOCIETY

*Honoring individuals who have made provisions for the Phoenix Society within their estate plans or life income plans. Have you remembered the Phoenix Society? Please let us know so we can include you in our Benefactors Society.*

Sarah Bazey, BA, OPM  
Bruce Berger  
Gary D. Boller Trust  
Deborah L. Bostic  
Alan and Delwyn Breslau  
John P. Capanna  
Manuel Carreras  
Antoinette M. Coppola  
Suzanne, Jason, Eric, Lynne & Kari DeLorenzo

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# Phoenix Society Announces Newly Elected Officers, Board Members

The following individuals were recently elected to serve as officers of the Phoenix Society board of directors:

**Lorraine Carli** was recently elected president of the Phoenix Society for Burn Survivors board of directors. Lorraine is vice president of Outreach and Advocacy for NFPA. She is president of the Home Fire Sprinkler Coalition (HFSC) and serves on the boards for The Center of Campus Fire Safety and Electric Safety Foundation International.

**Karen Colligan**, founder and principal of PeopleThink and a burn survivor, was elected vice president of the Society. Karen is a recognized

expert in leadership, team effectiveness, and organizational development.

**Peg Paul**, the communications manager for Home Fire Sprinkler Coalition, was elected secretary. She is the owner and director of Peg Paul & Associates, a marketing communications agency that specializes in developing and implementing multi-integrated information and education campaigns. Recognized by the American Fire Sprinkler Association

in 2014 as Fire Sprinkler Advocate of the Year. She has established a niche in public safety promotion.

**Tony Burke**, who was in the fire service for nearly 20 years, including 14 years as a career firefighter in Coquitlam, British Columbia, was elected treasurer. Tony served as the volunteer executive director of the BC Professional Fire Fighters' Burn Fund, was appointed to the International Association of Fire Fighters' Burn Foundation, and has worked with the American Red Cross.

In addition, the following individuals were recently added as new board members:



**Dean Elliott, JD**

*Vice President, Corporate Compliance & General Counsel  
AlloSource  
Centennial, Colorado*

Dean Elliott currently serves as AlloSource's vice president of corporate compliance, leading initiatives such as clinical research, regulatory policy, corporate compliance, litigation, and contract management. Dean, who plays a key role in ensuring the company is operating in line with regulatory and legal processes to honor the gift of tissue donation, is inspired by the gift of donation because it enables the lives of patients and their families to be forever changed. Dean has worked in the healthcare industry managing products, sales and distribution channels, regulatory matters, personnel and general business practices to maximize the profit and loss of corporations for more than 30 years.



**Victor C. Joe, MD, FACS, FCCP**

*Associate Clinical Professor of Surgery  
Director, UC Irvine Regional Burn Center  
University of California, Irvine Medical  
Center  
Orange, California*

Dr. Victor Joe is a Board-certified general surgeon with added qualifications in surgical critical care. He is the medical director of the UC Irvine Regional Burn Center, and he is a practicing trauma, burn and general surgeon. Dr. Joe is also an associate clinical professor of surgery at the UC Irvine School of Medicine. Before joining UCI in March 2013, he was the medical director of the Hirschman Burn Center and associate director of trauma at Arrowhead Regional Medical Center.



**Sheryl Ramstad, RN, PHN, MN, JD**

*Burn Survivor  
Peer Support Representative  
Saint Paul, Minnesota*

After nearly 40 years as a federal prosecutor, public defender, commercial litigator, trial judge, and Commissioner of the Minnesota Department of Corrections, Sheryl Ramstad returned to school to attain her master of nursing degree in 2013. Sheryl had been severely burned over 30% of her body in an airplane crash when she was 29 years old. Motivated by her desire to give back, she now serves as a Phoenix SOAR coordinator at St. Paul Regions Hospital where she was a patient. She is also working on her doctorate in nursing practice with a focus on health innovation and leadership at the University of Minnesota. Sheryl is committed to working with burn survivors worldwide through her medical mission work. In addition, she works as an RN at two homeless shelters for runaway youth in St. Paul, Minnesota.



# Join the Paradigm Challenge for a chance to win \$250,000

The Paradigm Challenge is an annual competition that inspires youth innovation to address important social issues. This year's challenge aims to generate new ideas to prevent injuries and fatalities from home fires—America's #1 disaster threat. Youth aged 7 to 18 are encouraged to participate; final entries are due May 1, 2016. To learn more about the challenge, visit [www.projectparadigm.org](http://www.projectparadigm.org).

## CHALLENGE TIMELINE

<b>May 1, 2016</b> Deadline for entries	<b>May 11, 2016</b> 100 finalists announced	<b>May 11-15, 2016</b> Public voting	<b>June 1, 2016</b> Final winners announced	<b>Summer 2016</b> Awards ceremony
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# Board of Directors

## Officers

**Lorraine Carli, President**  
Vice President of Outreach and Advocacy  
National Fire Protection Association  
Quincy, MA

**Karen Colligan, Vice President**  
Burn Survivor  
Founder & Principal, PeopleThink  
San Francisco, CA

**Anthony F. Burke, Treasurer**  
Volunteer  
Sioux Falls, SD

**Peg Paul, Secretary**  
President, Peg Paul & Associates  
Frankfort, IL

## Directors

**Karen Badger, PhD, MSW**  
Assistant Provost and Associate Dean in  
Undergraduate Education  
Associate Professor of Social Work  
University of Kentucky  
Lexington, KY

**Donald Cheley**  
President, Cheley Colorado Camps  
Denver, CO

**Dean Elliott, JD**  
Vice President, Corporate Compliance &  
General Counsel  
AlloSource  
Centennial, CO

**Patrick C. Horan, Past President**  
Burn Survivor and Volunteer  
Sparta, NJ

**Victor C. Joe, MD, FACS, FCCP**  
Associate Clinical Professor of Surgery  
Director, UC Irvine Regional Burn Center  
University of California, Irvine Medical Center  
Orange, CA

**William Leahy**  
President, New York Firefighters  
Burn Center Foundation  
New York, NY

**J.R. Martinez**  
Burn Survivor, Retired Military, and Actor  
Studio City, CA

**Amar Patel, DHSc, MS, NREMT-P**  
Director, Center for Innovative Learning  
WakeMed Health & Hospitals  
Adjunct Instructor  
UNC School of Medicine  
Raleigh, NC

**Sheryl Ramstad, RN, PHN, MN, JD**  
Burn Survivor  
Peer Support Representative  
Regions Hospital Burn Center  
St. Paul, MN

**Jill Sproul, RN, MS**  
Burn Survivor  
Nurse Manager  
Regional Burn Center at Santa Clara Valley  
Medical Center  
San Jose, CA

**Mike Williams**  
Burn Survivor  
Investigator, Harnett County Sheriff's Office  
Vol. Firefighter, Northwest Harnett Fire Dept  
Fuquay Varina, NC

## Contact Information

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## Staff

- Amy Acton**, Executive Director
- Sara Bruinsma**, Administrative Assistant
- Amy Clark**, Strategic Initiatives Director
- Maura Crevier**, Development Associate
- Megan Geerling**, Development Specialist
- Kerri Hanson**, Office Manager
- Jess Irven**, Adult & Support Services Program Manager
- Jeanne LaSargeBono**, Business Director
- Andrea Marz**, Executive Assistant
- Dayna Neff**, Development Director
- Nicole Perry**, Youth & Family Services Program Manager
- Pam Peterson**, Program Director
- Tammy VanMeter**, Database Coordinator
- Susan Wise**, Administrative Assistant

**Trish Acton**, *Phoenix Burn Support Magazine*  
Layout & Design

**Maureen Kalil**, *Phoenix Burn Support Magazine*  
Editor

**Note:** The Phoenix Society does not endorse products or services, but is committed to providing information as it relates to the burn community.

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Phoenix Society  
*for burn survivors*

Phoenix World Burn Congress

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