Phoenix Society
for burn survivors

Phoenix Burn Support Magazine

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Today at 52 years old, after years of living in the skin I’m in, I’m much more comfortable with having ashes on my feet; dirty feet don’t bother me much anymore. But it wasn’t always that way...

I was 17 years old and it was during a snowstorm when my car was rear ended and the gas tank exploded. I was trapped inside until miraculously an angel named Harold pulled me out. I was taken down to Regions Hospital Burn Center in St. Paul, Minnesota, with second- and third-degree burns on 21% of my body, with my face having some of the deepest.

The Unforgettable Intensity of Pain
I was inpatient for 2 months and had two skin graftings. It seems most burn survivors have one or two “worst memories” of pain from their time on a burn center, and, I too, have mine. Like when a donor dressing became infected and was removed with little pain medication. Like when the sutures were taken out of my face by a less than friendly resident. Like the final day in the tub when they cleaned my burns thoroughly. The little pain medication they used in those days was of no help; it was an intensity of pain I will never forget.

What got me through those inpatient days? Family, friends, and the burn center staff...people who brought caring, hope, and humor. People who brought splashes of color into a world that had become incredibly dark.

The Challenges of Emotional Healing
While the pain on the burn center was unbelievable, the emotional healing was equally as devastating. I remember clearly the first time I saw myself after I was grafted. They got me out of bed, set me in a chair next to the bedside table, and put a mirror in front of me. I looked in the mirror and I was horrified. The first thing I thought was, “I don’t look like a girl anymore, I look like a man who has had the daylights beaten out of him,” and then I thought, “Who is ever going to love me?” I was sure I would be alone for the rest of my life.

What I wouldn’t have given to have someone help me to know that my face would change, to support me in my fears, and to help me know I wasn’t alone. Like someone from the Phoenix Society’s SOAR Program; a peer support volunteer who has walked the path before.

After 2 months on the unit and two skin graftings I went home with pressure garments and a clear plastic face mask. There was no such thing as support groups, websites, retreats, conferences, school/social reentry, or social skills training. Leaving the security of the burn center, where everyone knew about burns, was terrifying. Everything I was afraid would happen happened. People laughed, stared, pointed, asked the most inappropriate questions, and made rude, hurtful comments. Again, I felt so alone.

It’s not that my family didn’t support me, but they were ill-equipped to deal with reentry into life as I was—as many burn survivor families are. My family is a loving and fun family. We love storytelling and music. We laugh together and have many happy and loving memories. However, talking about heavy feelings, such as fear,
sadness, anger, or dealing with tension or conflict, was not our strong point. We avoided it at all costs. We dealt with it poorly. Such as the time when I was walking through a mall and a couple of boys made me the brunt of their jokes—they laughed, pointed, and made rude remarks. My sister, bless her heart, became enraged and yelled back at them, “What the *&@ are you looking at?” I was as embarrassed as her response as I was theirs. I was also grateful for her protection.

What I wouldn't have given to have a program to help both my family and I deal with going out in public and responding to other people's reactions and questions, such as the Phoenix Society's Beyond Surviving: Tools for Thriving.

As burn survivors do, I settled back into a new kind of life and faced the challenges that burn recovery requires. Going back to school was a nightmare. Kids I had known since kindergarten, gone to birthday parties with throughout the years, wouldn't look at me and, in fact, turned away when I walked down the halls. They were as scared of me as I was of them.

What I wouldn't have given to have someone do a school reentry program for me and them, (ie, the Phoenix Society's Journey Back School Reentry program) and to have had a camp to go to where I'd meet other kids who were dealing with the same issues.

Several months after I was home, I decided that no one was ever going to want to be intimate with me so I decided that I would find someone who would have sex despite how I looked. I knew there were guys who would. I arranged the whole thing. The night of my graduation party, when I and others were drunk, I asked an older guy if he wanted to “do it.” He said yes and away we drove into the middle of nowhere and had sex. My first time. When I think of it now I feel sad...all I wanted was to feel loved, but it was the furthest thing from intimacy that it could have been.

What I wouldn't have given to have someone tell me that I would find love, that someone would cherish me and want to share in an intimate and loving relationship.

The Path to Recovery
But as we all do on the path of recovery, I moved on the best I could using the tools I had. I would at times party and drink heavily and at times isolate from everyone. Either way, I seemed to always end up feeling depressed and alone, and realized after 7 years I was a wreck. I was lucky enough to know one person who talked to me about emotions and healing; she changed my life. The most important thing I learned from her—to say no.

What I wouldn't have given to have a support group to help me then. Or the Phoenix Society website, the Phoenix Burn Support Magazine, or a Wednesday night chat as resources to help me as I walked the path of recovery.

After I learned to say no, there was no stopping me. I learned about the beauty of feeling my feelings, of finding self-confidence, of building a support system of people who loved me, and I learned that I had skills and abilities that helped me find purpose in the world. Granted, it took me another 10 years to do these things, but as I did, I noticed that the path was no longer gray with ash, but green with life.

It was 10 years after my accident that I started having flashbacks about the burn center and panic attacks about getting burned again. I felt crazy. How could this be happening after all the work I'd done to get “healthy”? Today I look at it like there was a part of me that needed more healing, but back then all I could do to deal with the PTSD (post-traumatic stress disorder) was to find a therapist and address the feelings and fears I had.

Was it scary? Sometimes, but it was also amazing. Was it hard? Sometimes, but my therapist was with me through it all. I wasn't alone... I wasn't alone. And what I learned: Sometimes you have to be willing to stop and clean a little of the ash off your feet. The secret: it's much easier to do with someone by your side.

A Commitment to Help Others
Fast forward another 10 years: I'm married with two toddlers, and working part-time as a counselor. One day as I walk in the door I learn that my brother was burned in a propane explosion. Words cannot describe the shock. Same hospital, same doctor, same amount of burns. A different experience for Jeff though—more pain medication, fast grafting, faster healing. As I watched him go through his trauma and recovery I did not have flashbacks, nightmares, or traumatic responses... I had done enough healing to not get triggered. Burn care had changed, and I had changed—so much so that a short time later I went to our burn surgeon and said, "I think I would be an asset to the burn center, I think you should hire me!"

A year later I started working at Regions Hospital Burn Center as a burn support representative, offering support, coaching, and programming for burn patients and their families, both in- and out-patient. I became involved with the Phoenix Society and have spent the past 13 years promoting recovery for burn survivors, family members, burn care professionals, and EMS/firefighters. It has been a privilege to help those whose lives have become covered with ash to know there is hope. To know there is color in the world besides gray. To know there is someone who will walk through the ashes with them.
Eight strangers made their way to the meeting room at the Omni Hotel in Providence, Rhode Island. They had come for the Creative Expressions workshop at the Phoenix Society’s 25th Annual World Burn Congress. Each person noted the unusual set-up as they entered the room. Chairs were placed in a circle and conga drums or African djembe were placed in front of each chair.

Evelyn Pinder, a certified music therapist, explained, “We’ll begin today with a drum circle. It’s a great way to break the ice with a group.” She started by teaching a simple rhythm. Thump, thump, thoink. Thump, thump, thoink. Thump-a, thump-a, thump-a, thump-a, thump, thump, thoink.

Soon Cheryl, Frances, Piotr, and Marcellus were mimicking her movements and the sounds she made with her drum, while Mike, Deb, Barb, and Kathy experimented with the dynamics of playing loudly and softly.

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“There are many somewhat academic definitions of music therapy,” Evelyn said. “But the definition I like best is using music to accomplish nonmusical goals.” She explained that music therapy can increase peer support and cohesion within a group. It can also increase self-esteem and self-confidence, especially during such periods as recovery from trauma and reintegration into society.

Amidst a constant beat of thumps and thoinks, each person in the group took a turn at playing a solo. Furrowed brows were replaced by smiles and laughter. Even the most timid members relished a moment in the spotlight when their turn came to tap out a solo. The group had become more relaxed, confident, and cohesive in just a few minutes.

When the drum circle ended, Amy Kinney from PeaceLove Studios in Providence, Rhode Island, led an art therapy exercise called “visual journaling.”

“Theory it’s called journaling, it’s not really about writing,” Amy explained. “By drawing instead of writing, you access the part of your brain that doesn’t have a voice. The technique is called access, release, transform, or ART therapy.”

Before they started drawing, Amy asked participants to set an intention, such as “I intend to connect with the feeling of tension in my stomach when I meet new people.” Then she led the group in a guided meditation to help quiet the mind. She encouraged them to see what images and feelings came up when looking with the “inner eye.”

After the guided visualization, participants began drawing intently, recreating the images in their minds and hearts. Some drew distinct objects, such as faces or trees. Others drew shapes and lines and took their inspiration from the process of moving their hands across the page.

The final step of the exercise involved looking at the drawing and reflecting on its meaning. Questions such as “How do you feel when looking at this piece of artwork?” or “What does the choice of colors and shapes tell you about the emotions expressed in the artwork?” provided an opportunity to gain new insight.
Participants reflected on their drawings individually and shared with others in their group. Amy moved through the room looking at the drawings and listening to the interpretations.

“It looks like each of you has taken a situation or image that was dark,” she remarked, “but then you’ve transformed it with color and light and movement into something positive.” She explained that most people don’t get to the step of transformation until the second drawing.

“Typically the first drawing is very dark,” Amy explained. “It’s the one where you release your negative thoughts and emotions. Then in the second drawing you work on techniques to reframe or transform the way you see the dark situation.”

The group of burn survivors, parents of burn survivors, health care providers, and volunteers was not surprised to see that they had moved to the stage of transformation on the first attempt. “We’ve had a lot of practice,” one person explained.

Evelyn closed the session with another music therapy activity. “This time we’re going to write a song as a group,” she said. She gave each person a version of the song “I Can See Clearly Now” by Johnny Nash, with blanks in the lyrics. They filled in the blanks by thinking about a current situation in their life.

The group sang 8 different versions of the song, which begins “I think I can make it now the pain has gone. All of the bad feelings have disappeared,” and ended each with “It’s gonna be a bright, bright, bright, sunshiny day.”

When the song ended, the survivors agreed. It truly had become a bright, sunshiny day.

More information on art therapy can be found on the following websites:
American Art Therapy Association: www.arttherapy.org
PeaceLove Studios: www.peacelovestudios.com

Activities and Treatment Modalities That Facilitate Healing Trauma
Megan Bronson, PMHCNS-BC

The overriding goal of recovering emotionally and psychologically from trauma is to help the brain to move out of a state of threat and to release the emotional pain and physical tension trapped in the state of trauma. There are many activities and treatment modalities that facilitate recovering from and healing the effects of trauma. Several are mentioned in the article, “Healing Trauma through Art Therapy and Creative Expression.”

There are treatments, modalities, and activities that are very effective in assisting the brain to achieve an equilibrium and a state of calm. Some of these require the help of a professional with expertise and training in treating trauma and some are activities that you can do on your own. A combination of these two can be very effective in shifting the brain and body out of a state of trauma.

Effective Treatment Modalities for Healing Effects of Trauma
Research has shown that the two most effective treatment modalities for healing the effects of trauma are cognitive behavioral therapy (CBT), and eye movement desensitization reprocessing (EMDR). There are many professionals who have training in utilizing one or both of these methods for assisting trauma survivors. Be sure to seek out a professional who has expertise and a level of comfort in working with complex trauma. (See “Getting the Most Out of Counseling After a Burn Injury” in the online Resource Center of the Phoenix Society website, www.phoenix-society.org/resources/resource-center/.) The websites for CBT (www.nacbt.org) and EMDR (www.emdria.org) can help you find counselors in your area who are trained in these two methods.

Activities You Can Do on Your Own To Help Your Brain Achieve a State of Calm

• Participate in creative expression of any sort, such as art, play, dance, journaling, narrative writing.
• Read books that inspire you.
• Pray, meditate, connect with nature and art, garden, etc.
• Practice yoga, tai chi, etc.
• Build a supportive network, (family, community, friends, church community, 12-step programs).
• Distance yourself from or leave unhealthy relationships.
• Set your intention on healing and growth. Set small goals that support recovery.
• Connect with resources available through the Phoenix Society website.
• Participate in Phoenix Society programs, such as the World Burn Congress and the UBelong children and adolescent program.
• Get involved in burn camps, retreats, and support groups.
• Balance solitude and connecting with others.
• Reach out and help someone else.
The Family Workshop at WBC: Sharing Our Collective Story

By Brad Jackson, PhD, and Carla Oliver, MSW, CCLS

Workshop Moderators

What a privilege for us to share together during the Family and Parent Workshop at World Burn Congress in Providence! We gathered—as parents, grandparents, caregivers, aunts and uncles, brothers and sisters, burn care professionals, burn survivors, boyfriends and girlfriends—to share our collective stories.

We began with the assumption and firm belief that the knowledge and skills already exist within our community for recovering, coping, and healing. Our hope was to provide an opportunity to share stories, lessons of life, and skills of living. Our hopes were realized and we had the pleasure of co-creating a “document” of our collective story that we are excited to pass along to others.

Telling Our Individual Stories

When we tell our individual stories, we often have choices about how deep we go and how much we share. It’s great to have levels of stories we tell about ourselves:

1. The short story—Use three sentences (Rehearse Your Response)
2. The story you tell those with whom you are close
3. The story you tell someone who really “gets it,” someone who has shared that experience, someone who has been in your shoes

Families had lots to say about the ways they can tell someone is really, truly interested and ready to listen, and when they are really, truly not. Trusting intuition can be really important when deciding what you share about yourself and your children.

Using Available Resources

The Phoenix Society website provides an ever-growing body of resources for parents, caregivers, and families, including the videos and interactive educational materials in Beyond Surviving: Tools for Thriving After a Burn Injury, the personal stories in the Support Network, and the Online Chats/support services available for online community members. During the workshop, we took an online tour of the website and talked about the ways these resources can support individuals in telling their own stories and also in sharing our collective story.

Listening for Strengths

Narrative therapy suggests that we each carry and often tell the stories of the problems that we have experienced. However, connected to those “problem” stories are “preferred” stories where something different occurred, something new happened, a hoped-for outcome appeared, or a different ending was written, even if just one time. As parents and families who have faced a burn injury, there are often parts of our stories and experiences that we share in common: fear, uncertainty, loss, grief, guilt, feeling starved for information, and searching for support. However, if we listen carefully, we also hear about turning points, important people who have had an impact on our lives, what we’ve learned through facing tough times, strengths that emerged, and the ways we maintained and fostered hope. These “preferred” stories need to be told as well to remind ourselves how we’ve endured, how we’ve grown, how our children have grown, and how we can shine a light on the path for other families facing a dark time.

We believe that the sharing of stories can be personally empowering and that sharing them together also summons our collective healing power. Jill Freedman and Gene Combs, narrative therapists and community consultants, have suggested that all of us have a choice in who and what we include in our life on an ongoing basis. In order for a person or an event to be an active and vivid member or part of our life, we can actively remember him or her or them or it. The family workshop asked participants to find a partner, or a group of 3-4 people, and interview each other in a remembering exercise about their burn injury experience.

Each person responded to the following series of questions within the small group (adapted from Freedman and Combs):

1. At the time of the burn injury experience, who was an important person in your life that helped you to get through it all?
2. What did that person show you that it was possible to do or think or feel?
3. What did she or he know about you that you sometimes don't know about yourself?
4. As you think back about the burn injury experience and see how far you've come, what do you notice or learn about yourself?
5. What does having that quality or those qualities mean for you as a person?

Telling Our Collective Story

When we gathered back together as a large group, we asked everyone to share the qualities and strengths that were shining through, the phrases or words that stood out in people’s stories, the images that came to mind as they spoke and listened.
And finally, we asked the group to help develop a “document” of our collective story by writing words, phrases, qualities, strengths, or poems on butterfly-shaped pieces of paper. We also offered space for images and symbols that represent our personal and collective experiences to become a part of this document. The butterflies were then added together in a kinetic sculpture to form a kaleidoscope of butterflies.

Here is a glimpse of our collective story:

Hope Forgive Faith Purpose Compassion Acceptance Love
Wisdom Family Strength Mom Courage Healing Joy
Happiness Reborn Life Happyhappyhappy
Connecting with others, Allowing others to be in control
Stay Strong Be Strong, You can do it
Family Knowledge Commitment Anger
Teamwork
Growth 2-20-03
Letting go of the guilt
Trial, process, faith, peace
Journey, pain, strength
Bearing witness to suffering
Symbols of a flower, a heart, male/female
Love...unconditional
Resilient
It’s not about waiting for the storm to pass but rather learning to dance within and through the rain.

After the workshop, the butterflies truly began to live in the UBelong Family Program, where the young participants had the chance to see the symbols of their parents’ and families’ strengths. The children and teens at UBelong added their own words to the sculpture and the collective story grew.

As we share our collective story of healing, we can help others learn what they need to know about us, but in the process we often learn more about ourselves.

References/Additional Resources on Narrative Therapy Approaches


More Than Meets the Eye: Learning to Live With Hidden Burns

By Kathy Edwards, PhD

Those who meet Elaina Meier or David Vogel for the first time don’t realize they are burn survivors. The scars that tell their stories at a glance have faded or are covered by clothing. It’s only when you hear Elaina talk about facilitating the Phoenix Society for Burn Survivors’ online chat or David talk about working with a burn survivor support group in Boston that you realize there’s more to the story.

Facing a Unique Set of Challenges

“Hidden” burns present a unique set of challenges for burn survivors. He or she may not be “seen” by others as a burn survivor, which, according to both Elaina and David, can have its advantages and disadvantages.

Because the scars can be covered by clothing, talking about the injury is optional. They can choose when and where to tell the story, or choose to not tell it at all.

However, the question of whether to “show or “not show” their scars may create an inordinate amount of angst when they consider wearing bathing suits, shorts, sandals, or sleeveless tops. They may struggle with intimacy and wonder how and when to talk about their burn injury in new romantic relationships.

Adapting to a New You

David recalls that after he left the rehab hospital many people didn’t understand the extent of his injuries or the reason for his lengthy hospitalization and recovery. Given what he’d been through, he was struck by the indifference shown to him by his coworkers and acquaintances.

He had been in a drug-induced coma for weeks due to burns from a house fire. He suffered smoke inhalation and had to relearn how to breathe and swallow on his own. He went through withdrawal from morphine and pain management drugs. There were moments that sent his whole body into a panic, like the time he burned his finger on the stove or when he smelled smoke from a chimney while walking down the street.

For the first year, David wore pressure garments and looked like a burn survivor. He remembers seeing people stare and hesitate when he went to shake hands. Gradually his hair grew back and covered the parts of his ears where cartilage was missing. Over time his grafts began to fade and fewer people noticed that he looked different. It surprised him when he realized that many people no longer saw him as a burn survivor.

“There is a window of time when people empathize with a burn injury, but the healing process takes much longer than that,” David reflects. “Once you look normal, you are expected to be over it.”

Although David could see the positive side to the dwindling reactions, it required yet another adjustment to his self-concept and body image.

David says that since his burn injury and recovery he has more empathy for others. “We all carry hidden traumas and even when you see a survivor with very visible scars, you are only seeing some of the injury,” he has realized. “A burn survivor may have lost loved ones in a fire. You can’t see that from the outside.”

At the time of her injury, Elaina was a college athlete. But returning to the locker room was difficult, not only because of her scars but because she no longer felt like
an athlete. However, in the process of losing weight, regaining range of motion, and rebuilding muscle after her burn, Elaina learned to appreciate and value parts of her body she had not valued previously.

“Instead of fixating on my scars, I learned to look at the things about my body that I liked,” she explains. “Before I looked in the mirror, I set my focus and intention on seeing the positive things instead of fixating on my scars. In time I was able to see the positive aspects of my body image instead of the scars.”

Ann Cook, MSW, a social worker at the Intermountain Burn Center, echoes the value of those positive messages. “It’s human nature to focus on the negatives and to have negative self-talk. We need to work to give ourselves positive messages.”

Ann recommends a new app, Red Dot Now (available for iPhone and Android), that is designed to help create positive changes and counter negative self-talk. (Note: This app requires a fee to download. Other similar useful resources may be available on the Web free of charge.) The app buzzes throughout the day and asks you to stop and examine what you are thinking and feeling at that moment. When you have a strong image about something, ask yourself, “Is it real? Is it true in this moment?” Learn to accept the situation and respond, “It is what it is, so how can I manage it?”

Ann suggests that it is better to say, “I’m managing the issue” than to say, “I’m struggling with the issue.” She encourages burn survivors to remember that everyone has something that makes them feel insecure about their body image. “You may have a friend who’s had a mastectomy because of breast cancer. Or someone who has hidden surgical scars they feel ashamed of, or a skin condition,” she points out. Everyone has challenges to overcome.

When you start to feel self-conscious, it can help to realize that you are probably focusing on the flaws much more than other people are, she suggests. To illustrate that point, Ann recalled a conversation between two teenagers attending a burn camp. The young man said he felt embarrassed by the burns on his legs and thought people believed he was ugly and weird. The young female camper responded, “This is your issue. No one else is thinking that about you.”

Elaina found that it took time to adapt to a new body image. She had to go at her own pace. “There were times and seasons when folks wanted to force the issue and I wasn’t ready,” she recalls.

Is It Necessary to Explain?

Elaina also spent time figuring out the best way to tell others about her burn injury. Both Elaina and David find it liberating that they no longer feel the need to tell everyone they meet about their burn injury. They have learned to tell their stories on a “need to know” basis.

After some trial and error and a few “Aha!” moments, Elaina is willing to share what has worked for her. “It’s definitely a challenge, especially in a dating situation,” Elaina says, “You don’t want it to be the thing you lead with, but you also don’t want to wait too long.”

Because her burns have become an integral part of her identity, Elaina feels that it shouldn’t be a stand-alone conversation. She suggests sharing information about the burn injury organically so it’s not a “honey, we need to talk” moment. Instead she might say something like, “I’ve got burn support next Tuesday and I’m looking forward to going so we can’t schedule anything else that night.” That statement is a cue that she experienced a burn injury and she’s okay talking about it.

Elaina suggests that the easiest way to start talking about a burn injury is to practice having the conversation with friends and family. “Build it into your day-to-day relationships in a way that’s balanced, that’s proportionate to where you are in your recovery,” Elaina says. Practicing with friends will make it easier to talk about burns in a romantic context.

Beyond Surviving Tools for Thriving After Burn Injury

Practice conversations, such as those recommended by Elaina Meier, are just one of the many strategies presented in Beyond Surviving: Tools for Thriving After Burn Injury. This course, offered through the Phoenix Society’s Online Learning Community, provides burn survivors and their families with the skills they need to be comfortable, confident, and competent in any social, work, or school situation. To access this program and other Online Learning content, all free of charge, visit and join the Online Community.

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Phoenix Society School Reentry Program Has New Look

For the past 7 years, the Phoenix Society has offered *The Journey Back*, a school re-entry program, to guide and support any caring adult in a young burn survivor’s life who wants to facilitate the child’s return to the classroom. The goal of *The Journey Back: Resources to Assist School Re-Entry* has been to ensure a positive return to school for the student and create an opportunity for a faster recovery of the child’s wellbeing by supporting the needs of the family, child, and school.

While a printed manual was a great option in 2007 when the program was originally launched, we soon came to realize that we could reach more people and improve our content by updating the way we delivered this important program. As a result, we have developed a new online version of this valuable resource. The revision includes all the content found in the original program, plus new information on supporting a child’s return to school after a traumatic loss. The following is now available through the Phoenix Society website, www.phoenix-society.org, in a user-friendly, convenient electronic format:

- **The Journey Back Tutorial**—a narrated overview of the school reentry program complete with video excerpts
- **The Journal Back Manual**—an e-book filled with information to support all aspects of a child’s recovery after burn injury or traumatic loss
- Additional content to support children who are suffering from grief and loss
- An expansive download library with video and printable tools to enhance your school reentry program

To access *The Journey Back: Resources to Assist School Re-Entry* (at no charge):

2. Click on “Access Tutorial.”
3. Log in to the Phoenix Society Online Community or if you haven’t yet joined the community, complete the short online form to do so.
4. Click on the “Self-Assign” tab and choose “The Journey Back: Tutorial.”
5. Fill out the brief pre-tutorial survey.
6. Complete the tutorial and the post-tutorial survey.
7. To access the Journey Back manual, click on “Access e-book.”
8. Fill out required contact and membership information.
9. Complete the manual’s pre-survey.
10. When you have completed the manual, fill out required post-survey on the Resources page (page 211).

For further support or information, contact the Phoenix Society at 1-800-888-2876.

**Reviewers Praise New Online Version of the Journey Back**

“I think this program has a large amount of resources for professionals to help guide a family in a school re-entry program. I love all of the downloads and documents available as resources.”

—Peyton Hutchins, MS, CCLS

“Both the input from the families and the summary of each section were very valuable!”

—Samantha Price, Mental health professional

“Very empowering.”

—Adult burn survivor

“It is a great tool and now it will even be better and more accessible.”

—Don Cheley, Phoenix Society board member

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Access the following Phoenix Online Learning programs at http://www.phoenix-society.org/community/stayconnected/online-learning-community/:

- Beyond Surviving: Tools for Thriving After Burn Injury
- Creative Cosmetics: Image Enhancement for Burn Survivors
- The Journey Back: Resources to Assist School Re-Entry
Ten years ago, on August 28, my life changed forever. My wife and two daughters, Gracie, 4, and Lily, 3, were in a plane crash. They were traveling to our cabin in southern Ontario. My wife, Kathryn, and the pilot, my brother-in-law, Charlie, did not survive. Miraculously Gracie and Lily did. However, the girls sustained broken bones, burn injuries, and, of course, the loss of the life they had known and their mother.

So much has happened in the last 10 years. It is almost incomprehensible to think about the journey that has been woven with grief, change, fear, surgeries, recovery, friendship beyond measure, limitless family support, new beginnings of my marriage to Katy, tears, laughter, intense feelings, anger, but always…hope. The 10-year anniversary of the crash has provided the opportunity to reflect and revisit, at times, some of the pain, but also the warmth of the support from family, friends, and the healing opportunities we have been provided through the Phoenix Society.

One thing I have learned over the past 10 years is that there are times in life when you need to be humble and accept help and there are times in life when you have the opportunity to give back. The 10-year anniversary marked an informative, growthful time period of my life. It was and is a time to give back and look forward for Gracie and Lily and toward their bright futures. Gracie now is 15, a freshman in high school, on the swim team. She is kind and full of wisdom. Lily is 13 years old, a 7th grader. She loves to swim, be with friends, and plans to go surfing in the ocean sometime soon.

To celebrate the 10th anniversary, Katy and I chose to raise money for the Phoenix Society by running a half-marathon. The phoenix rising up from the ashes, from adversity, is a sign of hope and resiliency. We wanted our run to be a tangible event that put a little more hope into the world, especially for other burn survivors, and for Grace and Lily.”
A SUPPORTED RECOVERY...
Your Membership Gift Helps Survivors Cope, Heal, and Thrive

As a supporting Phoenix Society member, you are making a tremendous difference in the lives of people in our community...people like Maudelle who received the help needed to accept her new image. She writes:

"I received facial burns that required grafting as a result of my burn injury in 1960. At the time there was no counseling offered as a part of a hospital burn recovery program. After 20 years of grieving the loss of my identity, I discovered the Phoenix Society in the early 80's and began to accept my new image. It is my wish that all burn survivors can benefit from these resources and support."

—Maudelle from Texas

Ensuring that every survivor and their family is supported in their healing journey is our goal as well. And it’s your member support that makes it possible. Your gift to the 2014 Spring Membership Drive will support the expansion of our online support services and resources as well as the Survivors Offering Assistance in Recovery program to 8 new locations. This makes support available online 24/7 and face-to-face peer support available at 70 hospitals by year-end. Gretta shares how offering the SOAR program has had a positive impact at their hospital:

"Since the Phoenix SOAR program was introduced at The Burn Center at Arkansas Children's Hospital, 21 survivors (all with stories of significant burn injuries, losing loved ones in the fire, struggling with grief and depression) have been trained to “offer assistance in recovery” for our new survivors. ...A friendship and mentoring partnership has developed."

—Gretta Wilkinson, RN

Please join us or renew your member support through the 2014 Spring Membership Drive and together we’ll build a future where no one recovers alone!

Make your gift today by:

Mail    Send a donation in the envelope provided in this issue
Online  Safe, secure, and available 24 hours a day at www.phoenix-society.org/donate
Phone   Call Megan Geerling at 800-888-2876

Toby and Katy after finishing the half-marathon as Team Phoenix members.
Employment After Burn Injury

Returning to work after a burn injury can be an important phase of recovery that helps you return to a routine. Work not only provides you with an income and other benefits such as health insurance, but can also give you a sense of purpose and confidence that is critical in maintaining a higher quality of life.

Returning to work is often accompanied by a confusing range of emotions, such as feeling both excitement and anxiety.

• You may not feel you are physically ready to return to work and do not have the stamina to work the same amount of hours or perform the same physically demanding tasks that you did before you were injured.

• If you were injured on the job, then returning to the same place of injury may lead to fears or anxiety related to the injury.

Many people begin the process of returning to work before they feel like they have completely recovered. This is because returning to work can be emotionally and physically therapeutic.

There are many resources available to help you return to work. Some of these resources vary according to your state law and whether or not you were injured on the job. Your eligibility for resources depend on your unique circumstances such as the severity of your burn injury and the demands of your job.

Remember that you are not alone. It is important to get assistance from the burn center, your employer, or other community resources to help you take the steps necessary to return to work safely and successfully.

Are you ready to return to work?
There are some important things that you can do to help make the process of returning to work easier:

• Talk with your health care provider about your readiness to return to work. He or she can help assess your current limitations and a reasonable time frame for returning to work.

• Spend time during your recovery period to focus on what you need to do emotionally and physically to return to work. This might include doing tasks around the house to build your strength and stamina, wearing work boots around the house to get comfortable in them again, particularly if you had a burn to the foot or leg.

• Getting prepared may also include counseling to help you cope with psychological and emotional issues you have about returning to work.

• You may feel uncomfortable about your change in appearance due to your burn injury, especially if your burns are highly visible such as on your face or hands.

• You may want to learn how to handle questions about your injury from your coworkers or employer.

• If you were injured on the job, counseling might focus on being prepared to return to the place where you were injured.
• Stay in touch with your employer and express your interest in getting back to work. Keep your employer informed about your recovery to ensure your job will be waiting for you when you are ready to return.
• Ask your health care provider to clearly evaluate your current work restrictions and communicate them to your employer.
• Provide your employer with a timeframe for when you may be able to return to work so your employer can plan accordingly.
• Consider asking your health care provider for a note to send to your employer with a timeframe for returning to work and list of supports (workplace accommodations) you may need.
• If you are not able to return to your job for a while, talk to your employer about jobs that you may be able to do during your recovery.
• See your health care provider regularly and follow through with treatment. Success with getting back to work requires active participation on your part.

Work conditioning programs
If your medical team determines that you are ready to return to work but you are lacking the stamina needed to do your work, you may participate in a return to work program that will gradually build your stamina for work, or be encouraged to do fitness training.

If your injury was work related, you might also be referred to participate in a work conditioning (work hardening) program. These are specialized programs run by occupational and physical therapists that aim to improve your strength and endurance to perform your job tasks.

Discuss options for improving your endurance for work with your health care providers since there are advantages and disadvantages to various approaches.

Workplace changes to help you return to work
Your medical team may ask your employer for a job description when you are ready to return to work. This job description is usually provided by the human resources department at your place of employment. The job description helps your medical team determine if you are physically capable of meeting the demands of your job, or if you need changes made at your workplace to accommodate your disability (accommodations).

It is OK to ask your employer for accommodations to help you return to work. Whether you were burned on the job or not, employers are legally obligated under the Americans with Disabilities Act and many state laws, to provide you with reasonable accommodations as long as it will not cause the business any undue hardship.
• Under the law, it is your responsibility to make the request for accommodations.
• Be prepared to advocate for yourself or find someone to advocate for you because your employer may not be familiar with the laws that require job accommodations.

• Your medical team may provide you with guidance and supporting paperwork to help you receive job accommodations.
• You have the right to refuse a job assignment that violates your doctor’s stated restrictions.

Typical workplace accommodations include:
• A modified work schedule (4 hours per day in the beginning, with a gradual increase to full-time).
• Working in a clean and dry environment.
• Limits on how much you can lift.
• Limited exposure to extreme environments (avoiding extreme heat or prolonged periods of cold).
• Altering work schedules to accommodate outpatient physical therapy and other medical appointments.
• Special software and hardware so a person with limited or no hand function can work on a computer.
• Adaptive equipment to help you perform your job tasks.
• Consider having your first day at work be in the middle of the week, rather than on a Monday. This short week will be less physically demanding for you.

These accommodations can make the initial transition back to work less demanding on you, and over the long haul, make it possible for you to succeed in your job. You may also need more recovery time when you get home at the end of the workday.

It may be helpful to educate your employer and co-workers about burn injuries so they are more understanding to your needs and have realistic expectations of your performance.

On-the-job Injury
If you were injured at work, you are likely covered by your state’s worker’s compensation insurance. Your case manager is responsible for making sure you get the benefits you are entitled to because of your on-the-job injury. Your case manager can help you get the treatment you need and make the transition back to work go more smoothly. He or she can also be a great resource in helping you to navigate the complex worker’s compensation system.

It is also important that you know your rights and be prepared to advocate for yourself. State worker’s compensation insurance differs by state. Your case manager may not provide you with all the information about what worker’s compensation benefits you are entitled to such as mileage compensation for doctor appointments.

Here are some things you can do to make this process run smoothly:
• Be sure to keep all your paperwork.
• It is important for you to know your claim number and to be in touch with your case manager regarding your treatment and your plan to return to work.
• Always keep your medical appointments to ensure your claim remains open.
• Remind your health care provider to send in the required worker’s compensation paperwork so your claim is not closed before you are ready to return to work.
• Do not ignore calls, mail or other forms of communication from your worker’s compensation program. Some of these communications may require you to take action.
• Make sure your case manager knows the name and address of your health care provider. Good communication between your health care provider, you, and your claims manager is essential to the smooth delivery of benefits.

Independent Medical Evaluation
The worker’s compensation case manager or your health care provider may request an Independent Medical Evaluation (IME). These are often done when the health care provider feels that you have recovered as much as you are likely to recover.

If you receive an IME, you would be referred to an outside health care provider who would independently assess if your condition is stable and no further treatment is appropriate. In that case, your claim is ready for closure.

Permanent Partial Disability Award
If your injury caused permanent loss of body function you will receive something called a “permanent partial disability award.” Any permanent partial disability award you receive is based on the degree of damage suffered, not on whether you can work.

Vocational Rehabilitation
Whether you were injured on the job or not, you may need vocational rehabilitation to help you return to work.

How does vocational rehabilitation work?
Vocational rehabilitation usually starts the first day you are admitted to the inpatient rehabilitation setting and continues after discharge, as the rehabilitation team and counselor continue to follow your employment status and provide help as necessary.

Vocational rehabilitation can also take place at any time an individual with a disability needs help finding employment. If your burn injury makes it difficult for you to get or keep a job, you may try to seek assistance from a vocational rehabilitation counselor.

Your vocational rehabilitation counselor may provide the following support to help you find a job:
• Assessing your skills, limitations, health needs, work and education histories, interests and even personality style.
• Helping you develop a plan that includes specific employment-related goals and how to achieve them.
• Setting up a “trial” work situation for you with a potential employer for a specified period of time to see if you are able to do the job, if you like the job, and what accommodations you might need.
• Helping you determine whether a potential job would be a good match for you. He or she can conduct a job analysis to determine the actual kinds of tasks done in that particular job, the cognitive (mental or thinking), social and physical demands of the job, and the need for accommodations.

How can you find a vocational rehabilitation counselor
• Ask your health care provider or burn center for a referral to a vocational counselor.
• The State Department of Vocational Rehabilitation agency (DVR) can be found in almost every state (see Resources). The DVR may also be able to help you train for a new career if you are unable to return to the job you had before your injury.

Vocational rehabilitation services vary by state. State DVRs are permitted to enter what is called an “order of selection” during difficult budget times, which means people with more severe disabilities will be given priority to receive services.

Long-Term Disability
Due to the severity of the injury, some people may not be able to return to any type of employment.

A person is eligible to receive disability payments from the Social Security Administration (SSA) if he or she is unable to perform any kind of work at a level of “substantial and gainful” activity and the disability is expected to last at least a year. The SSA pays disability benefits under two programs:
• Social Security Disability Insurance (SSDI) is a long-term disability insurance program funded by payroll taxes. Eligibility is based on your past work history and income. After a waiting period, SSDI recipients are eligible for Medicare.
• Supplementary Security Income (SSI) is a federal welfare program for people with disabilities who are unable to work and are poor. SSI recipients are eligible for Medicaid after one month.

If it seems unlikely that you will return to work within a year, we recommended that you apply for SSA benefits as soon as possible. If you have purchased a long term disability policy, you may also be eligible for benefits from that policy provider.
What will happen to your long-term disability benefits if you return to work?

Sometimes people are reluctant to start working because they don’t want to lose their medical benefits under SSDI or SSI, or because of the extra costs of getting to or staying at work. Several federal programs have been created to help avoid this situation. Federal work incentive programs under SSDI or SSI allow people with disabilities to receive benefits and federal healthcare (Medicare and/or Medicaid) while still keeping some of their earnings from employment.

Two federal work incentive programs that help people with disabilities secure a variety of supports such as job coaches, transportation, equipment, and work-site accommodations, include:

• PASS (Plan to Achieve Self Support) - This program (3 year max) allows funds used in achieving employment goals such as paying tuition for training courses to be excluded in calculating your monthly SSI benefits. Contact your local SSA office or for more information, go to http://www.socialsecurity.gov/pubs/11017.html

• IRWE (Impairment-Related Work Expenses) - IRWE benefits can be claimed for your entire working life. In this program, work-related expenses such as adaptive equipment or personal care costs can be deducted from your income so you can retain more of your SSI benefits.

Your rehabilitation counselor will be familiar with these programs and can help you apply.

The Law Protects You

The federal Americans with Disabilities Act (ADA) prohibits employers from discriminating against qualified individuals with disabilities who are able to perform the essential functions of the job with or without accommodations.

To be protected under this law, you must have a disability that limits major life activities.

• An employer must make “reasonable accommodation” to your disability if it would not impose an undue hardship on the business. Whether an accommodation is considered a hardship depends on the business size, financial resources, nature of operation and other factors.

• When you apply for a job, an employer cannot ask you about the existence, nature or severity of your disability, but can ask you about your ability to perform certain job functions, although some elements of your “disability” may be visible to others.

• An employer can require you to pass a medical examination only after a conditional offer of employment is made, and if it is job-related and required of all employees in similar jobs.

If you feel an employer has discriminated against you, contact the U.S. Equal Employment Opportunity Commission (EEOC). Call 1-800-669-4000 to find the office nearest you, or go to www.eeoc.gov. Many states have powerful disability rights laws as well.

Resources

Benefits for People with Disabilities, Social Security Administration.
1-800-772-1213 www.ssa.gov/disability

Find your local Vocational Rehabilitation Agency and other federal and state resources, contact the Job Accommodation Network, U.S. Department of Labor. 1-800-526-7234 http://askjan.org/pubsandres/res.htm

Equal Opportunity Employment Commission (ADA) 1-800-669-3362 www.eeoc.gov/

The Phoenix Society for Burn Survivors. 1-800-888-2876 www.phoenix-society.org

References


Source

Our information is based on research evidence whenever available and represents the consensus of expert opinion of the Burn Model System directors.

Authorship

Employment after Burn Injury was developed by Shelley A. Wiechman, Ph.D., and Sabina Brych, in collaboration with the University of Washington Model Systems Knowledge Translation Center.

Disclaimer

This information is not meant to replace the advice from a medical professional. You should consult your health care provider regarding specific medical concerns or treatment.

For more information, contact your nearest Burn Model Systems.

For a list of Burn Model Systems, go to: http://www.msktc.org/burn/model-system-centers

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A Spanish translation of this article can be found on the Phoenix Society website under “Vocational” at www.phoenix-society.org/resources/resource-center/
We Were Asked to Add Our Voices—Now We Must Respond
By Amy Acton, RN, BSN

Several years ago the Phoenix Society was asked to assemble a panel to share the survivor’s perspective on which issues should be considered as priorities in burn research over the next 10 years. The panel was to participate in a meeting attended by the top researchers and care providers in the burn community. My initial reaction was to wonder what I, or my fellow panelists, could add to this meeting. As a survivor and nurse I had spent my career at the bedside and in the community assisting burn survivors, not conducting research.

An Important Opportunity
However, as I thought about this opportunity, it became clear to me that this was a very important chance for the survivor community to share our collective experience about long-term recovery issues. I knew that much of the research on psychosocial recovery had focused primarily on the first 2 years following a burn injury and had identified issues that we at the Phoenix Society had been addressing as an organization. We understood that programs were available to help emotional recovery, however, our decades of experience at the Phoenix Society also told us that those initial 2 years after an injury were just the beginning of recovery for many. So in response to this request, we reached out to a number of survivors and their families to provide us with the insight we needed to focus our input for this meeting.

Phoenix Society members Chris Gilyard and Erin Mounsey joined me on the panel. We were scheduled to speak as the final presenters on the conference agenda. To say we were all a bit intimidated is an understatement, but we were also honored to be asked our opinions. We commended the research community for the valuable work already done, and we also highlighted the issues we felt deserved further research so that burn survivors could return to the fullest life possible.

Two Compelling Stories
The stories shared by Erin and Chris were especially poignant because, although they were burned more than 20 years apart, they recounted very similar challenges in their transition back to life. They described the specific interventions that had helped them to begin to address the challenges they faced, but stressed that these still were not a standard of care. They both found that peer support, as well as tools and programs to help with social reintegration, dealing with a changed body image, and the impact of trauma on families, were not fully embraced by care providers or readily accessible to those in need.

It was a powerful moment to hear about their real-life struggles and what had made the road less difficult. Their stories made it clear that there was much work to be done to work together as a burn community to solve these issues.

Our message stressed that there was a need to build upon the current research that indicated difficulties in social reintegration, and to work together to evaluate available programs, develop new interventions, and establish a sustainable way for survivors to access these resources.

A New Formal Role
This session inspired then-president of the American Burn Association, Dr. David Greenhalgh, to call for the formation of an ongoing formal committee with representatives from the ABA and the Phoenix Society that would ensure that survivors are influencing the identification of priorities in burn care research and participating as part of the team addressing them.

Personally, I have never felt more empowered as a survivor or as a front-line care provider implementing programs that support recovery then at that meeting. It was a key moment for the survivor community and for the Phoenix Society. As part of the leadership team of the only national burn survivor-based organization, it was a call to action to be further engaged in areas we had not been previously—research and advocacy for quality of care. Traditionally, we had focused on providing support and interventions that were reportedly helpful
Please visit the Phoenix Society website (www.phoenix-society.org) to learn more about how you may be able to help us with research and program evaluations. Help us achieve our goal of improving the quality of care.

**Evaluation of the UBelong Program for Children Impacted by a Burn Injury**

University of Kentucky College of Social Work

**Goals:**
- To evaluate the success of the UBelong program from the perspective of the children and teens participants in impacting areas such as self-perception, self-esteem, social comfort, and feelings of fitting in with others.
- To gather information from the participants about what works well in the program and how the program could be improved or finely tuned to best achieve its outcomes.

**Evaluation of Journey Back – School Re-entry Online Resource Delivery**

**Goal:** To collaborate with evaluation partners to learn the effectiveness of the program materials and the new online program delivery format.

**Evaluation of a Web-based Social Skills Training (SST) Program for Survivors of Burn Injury**

Department of Physical Medicine & Rehabilitation, UT Southwestern Medical Center

**Goals:**
- To examine benefits of a Social Skills Training program in reducing social anxiety and improving community participation.
- To assist burn survivors who experience difficulty in psychological and social adjustment.

**Take Charge of Burn Recovery - Pain Management Study**

Johns Hopkins University, Johns Hopkins Burn Center

**Goal:** To develop and test a new online program to help burn survivors manage their pain. Take Charge of Burn Recovery - Pain is a computer-based, online program that gives information and tips on how to manage pain following a burn injury.

**Measurement of Community Participation Using a Computer Adaptive Test in Adult Patients with Burns**

Boston University School of Public Health/Massachusetts General Hospital/Spaulding Rehabilitation Hospital/Phoenix Society.

**Goal:** To develop a consumer-based tool that assesses community re-integration following a burn injury. With the new instrument, our goal is for clinicians and consumers to be able to track the functional recovery of burn survivors in terms of their social integration in the community, their short- and long-term status, and to apply the measurement tool to new rehabilitation interventions in future research studies.

To our members, such as peer support, social re-entry interventions, and education of care providers. Over the years we were often asked to write letters supporting research projects, but we had not been involved in forming research projects that could ultimately lead to sustainable interventions and programs or validating those we were already providing.

The joint committee that Dr. Greenhalgh advocated for soon became a reality. Since then the Aftercare Reintegration Committee (ARC) has helped identify additional areas of needed research, emphasizing the evaluation of current model interventions, the development of new interventions and the education of burn care providers regarding the long-term needs of patients and families as priorities. By bringing together the researchers, care providers, and our organization, which delivers national programs, we have had the opportunity to not only understand the challenges in burn recovery but truly address them with interventions/
programs that will promote the best outcomes for those with burn injuries.

**Partners in Research**

Fast forward 7 years—we are no longer just writing letters of support for research but have become partners in the work being done. We have participated in the National Institute on Disability and Rehabilitation Research meeting in Washington, DC, for several years to share our current programs and ideas of how the model systems research could further support interventions that we believe have a positive impact on psychosocial recovery. We are actively engaged in several of the model systems research projects, sharing valuable perspectives during the formation of projects, collaborating to evaluate current interventions we are offering, and engaging our membership to evaluate new interventions that we hope to offer through our growing network. By expanding our participation and partnership with the burn research community, we will all have a greater impact on helping families and burn survivors get back to living after a burn injury.

**The Value of Your Voice**

Phoenix Society member involvement is crucial to this work. The size of our membership enables us to address one of the greatest challenges within burn care research—obtaining the number of subjects needed to conduct valid research. The Phoenix Society clearly has a network of burn care providers, survivors, and family members with a breadth of experience and passion for this work that is unparalleled. We are currently working with our partners on several research projects that will benefit from your involvement. We will be actively seeking participants in several evaluations and studies over the next year. We ask that when you receive an invitation to take part, you consider the value of your voice, feel the empowerment, and understand the impact you may have on the future of burn care if you choose to participate. We may not be researchers, but we live with a burn injury every day. We hold the keys to what will help us live the fullest life possible. Our voices will add tremendous value to focused research on long-term recovery—I understand that now.

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**Auction Items Needed!**

Our annual World Burn Congress silent auction is coming up! **Do you have sports memorabilia, artwork, vacation property, jewelry, or other items you’d like to donate?**

With your help, last year’s auction was our most successful to date and raised almost $15,000 for our World Burn Congress program. We look forward to another great year.

Please contact Sara Bruinsma at 800-888-2876 or Sara@phoenix-society.org with your donation information.

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**Hidden Burns continued from page 9**

**What About Intimacy?**

Ann suggests that a burn survivor’s response to intimacy has as much to do with their past experiences and feelings about intimacy as it does with the burn injury itself. Their feelings may be influenced by past experiences in relationships, values, and beliefs, as well as the messages they received about intimacy from their parents.

“Any time you reach for new goals, your unresolved issues may come up,” Ann explains. A new relationship can trigger unresolved issues about body image, intimacy, and trust.

“Think of the triggers as a gift because they make you aware of unconscious processes like anxiety or fear,” she suggests. “The triggers help you learn more about yourself and what’s going to be in your way.”

Some people may need professional help to move beyond the triggers into a place of growth. Others may find that energy-refocusing tools, such as yoga, meditation, Reiki, positive affirmations, visualizations, and breath work, can help overcome issues related to trauma, body image, and intimacy. These techniques create changes on the inside that influence the way you think about your body image and present yourself on the outside. Keep in mind that they are not only useful for people with hidden burns. Anyone who has experienced trauma, or had a hard time accepting their body image, or experienced fear when starting a new relationship may find it helpful to reframe the experience and channel energy in a positive direction.

For further information on this topic, see the Resource Center and Phoenix Programs sections of the Phoenix Society website, www.phoenix-society.org.
Spring is on the way and it’s a great time to join Team Phoenix!

It doesn't matter whether you run, walk, bike, or climb mountains, you can join Team Phoenix by participating in an event in your area and dedicating your efforts to burn survivor recovery. You can also join our feature teams in Chicago, Boston, and Big Sur, California. Learn more about becoming part of Team Phoenix at www.phoenix-society.org/teamphoenix or call Megan or Sara at 800-888-2876 today. They will also help you set up a personal fundraising web page so friends and family can easily support you.

By representing the Phoenix Society and the burn community, Team Phoenix allows all of us to raise awareness as one voice and provide funding for tools and support that help survivors and families across the nation live the fullest life possible!
We wish to thank the following individuals and organizations for their recent contributions:

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