Stories of Empowerment, Survival, Healing Recounted Throughout 25th World Burn Congress
Stories of Empowerment, Survival, Healing Recounted Throughout 25th World Burn Congress

By Kathy Edwards, PhD

“The best part about World Burn Congress is knowing I’m not alone—that other people are going through the same things I’m going through,” says Maryann, a first-time attendee.

“This is my third year. The thing I enjoy most is seeing the transformation people go through when they come to the World Burn Congress for the first time,” shares a nurse from Wisconsin. “Then it’s great to see how, after a few years, they come back and they are the ones to help the new people. That’s what keeps me coming back and bringing patients and their families from our burn center.”

“I’m the sister of a burn survivor and I work with our children’s camp,” another woman shares. “I got a lot out of one of the pre-conference workshops that talked about new treatments for scarring. I could see that there was a lot of hope among the burn survivors who attended the workshop when they learned what’s possible.”

Remembrance Walk Focuses on 10th Anniversary of Tragic RI Fire

As members of the burn community came together for the Phoenix Society’s 25th Annual World Burn Congress in Providence, Rhode Island, they continued a WBC tradition of remembering and honoring those who have been injured or killed in fires during a group walk. This year that walk focused on the victims and survivors of The Station nightclub fire, which occurred 10 years ago in nearby West Warwick.

The Walk of Remembrance concluded at the Rhode Island State House to honor those who died from their burn injuries and to remember the many ways the city of Providence and the state of Rhode Island were touched by the fire that broke out on February 4, 2003. Guest speakers included the current and former governors of Rhode Island, medical directors from the Rhode Island Burn Center and the Shrine’s Hospital for Children in Boston, firefighters from the city and the International Association of Fire Fighters, and survivors of The Station fire. They spoke about the depth of the tragedy and honored those who lost their lives. Speakers explained that they took heart from the tremendous outpouring of love and support from medical providers and the surrounding communities in the aftermath of the fire. Participants also used the event as a “call to action” to prevent further fire-related deaths and loss.

At the Congress’ opening ceremony the next day, Amy Acton, Executive Director of the Phoenix Society for Burn Survivors, shared, “Together our collective voice is being heard. I think we felt it last night when we marched to the State House of Rhode Island. I’ve never felt so empowered.”

Survivors, Family Members Share Their Journeys of Recovery

The themes of empowerment, survival, and healing echoed throughout the conference this year. Keynote speakers Lionel and Joanna Crowther shared the story of Lionel’s burn injury as a firefighter for the Manitoba (Canada) Fire Department and how it touched the life of each member of their family. Lionel and Joanna found that the journey of recovery was different for each of them.
“In my training in the fire service, there was a guidebook or training manual for almost everything,” Lionel recalls. “But when I experienced a severe burn injury, there was no manual for us to follow.”

Two other firefighters who served with Lionel were killed in the fire that day. Among the many issues he faced in recovery was the challenge of survivor’s guilt. He and Joanna spent about 3 years “surviving survival” as they worked to heal the physical and emotional scars and work through the changes in their family and in their relationship. (See related story, page 9.)

Today Lionel works with the fire service and with the Phoenix Society’s SOAR program to “help write the guidebook” for other firefighters and their families who experience a burn injury. The couple’s emotional message resonated with a receptive audience of others who’ve “been there.”

Keynote speaker Chris Gilyard echoed the need for emotional support and guidance, as she recounted the story of her burn injury and recovery 35 years ago. While the physical pain and recovery from the initial injury were intense, the emotional pain was equally devastating. Chris describes “feeling very alone” when she was released from the hospital. “There was no support group, or camp, or social skills training to help me,” she explained. Her family did their best, but they didn’t know how to help her with the stares and rude remarks she experienced.

When a relative experienced a burn injury years later, it was the catalyst that prompted Chris to “pay it forward by working as a burn survivor support representative at Region’s Hospital in Minnesota.” She also worked to bring the SOAR (Survivors Offering Assistance in Recovery) peer support program to other burn survivors, “so none of them have to go through this injury alone.” Today Chris works as a marriage and family therapist.

This year’s Congress offered more opportunities for participants to share their experiences with others. In addition to the open mic sharing sessions that have become the mainstay of the World Burn Congress, participants had the opportunity to meet in supportive groups designated for adults burned as children, burns related to abuse, caregivers supporting loved ones after discharge, burn-injured firefighters, survivors with hidden burns, and healthcare professionals.

Programs for the 873 attendees, including 357 first-time attendees, provided something for burn survivors and their family members of all ages. The UBelong program for survivors, children of burn survivors and siblings, 7 to 17 years of age, featured a skit and expert speaker on how to handle bullying. The 39 participants learned how to regain their power in a bullying situation and how to help a friend who is being bullied. The young survivors discussed what it means to be brave on the outside and on the inside and how to share their story with others. Participants created a video to the song “Brave,” which was shown at the closing ceremony on Saturday afternoon, sharing their thoughts on burn injuries with the entire Congress audience. In a continuing effort to provide programming that serves the whole family, the childcare program, attended by 14 younger children, focused on therapeutic activities this year, and a parent workshop targeted the unique needs of families.

**SOCIETY LEADERSHIP REPORTS ON THE YEAR’S ACHIEVEMENTS**

Support, advocacy, and giving back were addressed at the annual meeting of the Phoenix Society membership on Friday morning. Board member Vickie Pritchett reported that this year the Phoenix Society reached 45,000 people, raised $1.1 million from 1,378 donors, worked with 1,100 volunteers, and provided the SOAR peer support program by year-end 2012 to 55 hospital burn centers throughout North America.

Amy Acton followed up by explaining, “The more we do, the more we are asked to do. The challenge for the Phoenix Society is to figure out how to grow the organization so more burn survivors can receive peer support and the resources they need to survive and thrive.”

As a testament to the power of healing that occurs at the World Burn Congress, Joe Kinan, a burn survivor from The Station nightclub fire, spoke at the membership meeting and showed the public service announcement he made to help raise awareness, as well as funding to assist individuals who wanted to attend WBC in Rhode Island.

Amy explained, “Joe is a quiet friend. He went from being someone who didn’t want to speak in public or have his picture continued on page 8
Harman Philanthropic Leadership Award

Integra Foundation was selected as the 2013 recipient of the Harman Philanthropic Leadership Award. The philanthropic foundation was established in 2002 by Integra LifeSciences Holdings Corporation, a leader in the research, manufacturing and marketing of devices used in neuro-trauma and neurosurgery, reconstructive surgery, and general surgery, and many of which are dedicated to burn treatment.

“Their partnership with us is natural given their mission to improve the outcome and quality of life for patients and their communities,” remarked Megan Geerling, development director for the Phoenix Society. Since its establishment, the Integra Foundation’s generous donation of more than $100,000 has helped the Phoenix Society to expand the World Burn Congress programs and meet the needs of thousands who have been affected by burn injury. “Integra definitely embodies the spirit of philanthropic leadership that the Harman Award celebrates,” she added.

This award, named after long-time Society member Janet Harman, is presented by the Phoenix Society’s Board of Directors at the Phoenix Society’s World Burn Congress to an individual or family, corporation, foundation, or service organization with a proven record of exceptional generosity through direct financial support and/or volunteer effort. Awardees have demonstrated outstanding volunteer and charitable generosity that encourages others to take philanthropic leadership roles within the Phoenix Society for Burn Survivors so the Society can further its mission to support those impacted by burn trauma.

Annual Awards Recognize Service to Phoenix Society, Burn Community

At the recent World Burn Congress in Providence, Rhode Island, the recipients of 4 Phoenix Society awards were recognized for their significant contributions to the Society and the greater burn community.

Rick Halpert

Alan and Delwyn Breslau Award

Rick Halpert, an attorney with more than 40 years of personal injury and trial experience, was named the 2013 Alan and Delwyn Breslau Award recipient. Rick focuses his practice on representing burn survivors in burn injury litigation, as well as handling wrongful death and products liability matters. He has a long history of supporting the Phoenix Society, including serving as a member of the Society’s board of trustees from 1997 to 2005. During that time he was instrumental in organizing board retreats and developing the Society’s mission statement. He also played a key role, following the retirement of Society founder Alan Breslau, in the selection process of the Society’s first executive director. According to George Pessotti, a former Breslau awardee and Phoenix Society past president, Rick, through his “honesty, integrity, wisdom, pro bono work, and financial support,” has significantly enhanced the ability of the Society to fulfill its mission of peer support, education, and advocacy over the last 25 years.
Robert Feeney
Phoenix Society Advocacy Award

The 2013 Phoenix Society Advocacy Award was presented at World Burn Congress to Robert Feeney. Since his injury and the loss of his fianceé more than 10 years ago in Rhode Island’s Station nightclub fire, Rob has participated in the advocacy training program developed by the Phoenix Society and has used that training to effectively provide the burn survivor perspective to discussions of fire safety and fire prevention, including those in legislative arenas. In 2011 Rob appeared before the Chattanooga, Tennessee, City Council to speak in favor of the city adopting fire sprinkler regulations that would prevent the kind of tragic incident in which he was injured. Largely as a result of Rob’s testimony, the Chattanooga City Council passed the fire sprinkler requirement for sports bars and restaurants with live entertainment. In 2013 he worked diligently with those in Chattanooga to try to prevent reversal of the enacted fire sprinkler code. He has spoken at national meetings, such as the 2012 Vision 20/20 Models in Fire Prevention Symposium and the American Burn Association Partnership Conference. He joined with Common Voices and other fire service organizations to support the re-introduction of the Fire Sprinkler Incentive Act to the 113th Congress.

“Survivors like Rob Feeney, who are committed, trained Phoenix Society advocates are making a difference in our effort to address the fire problem in America,” said Phoenix Society Executive Director Amy Acton.

Gerald Dunn
Joe Hickey Fire Service Award

The Joe Hickey Fire Service Award honors a firefighter or firefighter burn foundation who provides assistance to burn survivors, demonstrates a commitment to improve burn care through all phases of recovery, and works to carry on the mission of the Society and local community. The recipient of the 2013 award, which is presented annually by the Phoenix Society in partnership with 11 other organizations, was Gerald Dunn. Phoenix Society President Patrick Horan explains that Jerry was selected for his “enthusiastic and visionary service.” Jerry has for many years dedicated himself to causes in the burn community through work with the Denver Fire Fighters Burn Foundation, the American Burn Association, and the International Association of Fire Fighters Burn Foundation. He has facilitated the cooperation between Denver firefighters and The Children’s Hospital in Denver, been personally involved with Cheley/Children’s Hospital Burn Camp, and spearheaded firefighter involvement in recovery through fundraising and volunteering. After more than 35 years of service to the fire department, Jerry retired in 2007. However, he continues to serve as a volunteer and advocate for developing a stronger burn community and Phoenix Society.
As its participants can confirm, the Phoenix Society’s World Burn Congress (WBC) creates a community that nurtures the common bonds among burn survivors. Burn survivors, regardless of their careers or other life circumstances, share similar steps to recovery and universal experiences, such as healing from trauma, grieving, and forgiveness.

The Phoenix Society acknowledges this shared experience among survivors, but also creates space for attendees at WBC to connect with others who share characteristics that are specific to their burn injury. For example, the programming at WBC includes special-topic support and discussion forums for such groups as adult burn survivors burned as children, survivors with “hidden” burns, and survivors who experienced electrical injuries.

**Partnerships Make It Possible**

The Society, through its partnerships with burn foundations, individual members of the fire service, and organizations such as the International Association of Fire Fighters (IAFF) Charitable Foundation Burn Fund, the National Fallen Firefighters Foundation (NFFF), and the University of Kentucky College of Social Work, has also worked to better meet the support needs of another group—burn-injured members of the fire service and their families.

**Firefighters Find Forum for Healing**

The fire service-related sessions at this year’s WBC included a support group for burn-injured firefighters (attended by about 30 firefighters), as well as one for their spouses (attended by about 16 spouses); a discussion group for all firefighters (attended by about 75 firefighters); and an In the Line of Duty panel, featuring Fire Capt. Luis Nevarez, firefighter Scott Atchison, and firefighter-spouse Amy Adams, which provided insight into the firefighter experience to all attendees. As part of a general session panel, Providence, Rhode Island, Fire Lt. Antiliano Estrella discussed advocacy efforts and fire code policy changes that stemmed from the tragic Station nightclub fire in 2003. Lionel Crowther, a Winnipeg, Manitoba (Canada), firefighter, and his wife Joanna also shared their story in the general session. In 2007, Lionel and another firefighter, were burned while operating at a house fire that also claimed the lives of 2 fire captains.

Establishing forums where firefighters and their families can share their experiences, thoughts, and express their feelings has been an important addition to WBC programming. Their impact and benefit can best be described in the words of several participants:

- Fire Lt. Paul Machado of the Fall River, Massachusetts, Fire Department was burned in March and attended WBC for the first time this year. He wrote that “it was great to meet everyone there and experience the conference. There was an instant connection meeting other firefighter burn survivors—they understand everything that has gone through my head. I was skeptical going in. I think you have to be here to get it—firefighters reaching out to and learning from the burn community. I’m now an advocate and will be sharing this with Brothers and Sisters.”

- Fire Lt. Joe Kalinowski of the Marshfield, Massachusetts, Fire Department was injured fighting a fire in November 2012. He commented on the bonds that exist among firefighters and, in particular, burn survivors in the fire service, saying, “The [WBC] sessions reinforced the fact that we are a family in our profession throughout North America. Regardless of the severity of our individual
injuries or stage of healing, as burn survivors we are a family that is able to support each other and share what we are experiencing or have experienced; unconditionally we have resources available to us.”

- Firefighter Atchison, also a first-time WBC attendee, who was partnered with Firefighter Crowther that tragic night in 2007, commented, “As part of the In Line of Duty panel, I gave the perspective of a firefighter who survived a tragic incident without burn injuries, as well as insight into the workplace the burn survivor firefighters would potentially be returning to. My wife, Sheri, was also able to attend with help from the Phoenix Society and she attended the spouse support groups that helped her greatly. We were truly and deeply inspired by the survivors, health care providers, and firemen we met.

“Going into the conference there was a feeling of apprehension as to my place with burn survivors as there are no physical scars on me. When you are a fireman, you can usually identify who has been in serious situations by looking at the gear of fellow firefighters. Some of the experienced guys will wear blackened helmets or gear that displays the wear and toil of prior incidents. My peers at the conference—both firefighter and non-firefighter—wore their blackened helmets everywhere they went in the form of physical scars. These scars gave unspoken stories of survival. After speaking on the panel and in support groups sharing the tragedy we experienced in Winnipeg, we heard the stories of some others. The internal scars, coping mechanisms, and healing processes of the survivors in this group became apparent, affirming the feeling of belonging only a group like this can bring. It helped us greatly. We felt very welcomed into this family of special individuals. Thank you very much to the Phoenix Society for helping us attend and creating such an incredible forum for healing.”

**Spouses Bond With Others Who Understand Journey**

Scott’s wife, Sheri, added to his comments from her perspective, saying, “This was my first conference at the Phoenix Society’s World Burn Congress and I have to admit that I wasn’t sure what to expect. For me personally, I didn’t realize that I buried my feelings/stress from the event until I attended a burn-injured firefighter spouse support group. This was the first exposure I ever had to feeling like I was “normal”—every spouse feeling the same feelings… I walked away from this event with a new purpose and a new light. There was a real benefit of attending the Phoenix Society’s World Burn Congress this year. The connections that I made felt so genuine, and I know they will carry me through the rough times ahead for me. I wouldn’t have even contemplated starting this emotional recovery journey if I hadn’t attended the firefighter-spouse-specific session. Firefighters are a special breed; while everyone else is running away from danger they thrive on running into danger. It is hardwired into them and you can’t change that, so to be able to communicate our fears with other spouses is a release for us.”

Phil Tammaro at In the Line of Duty, one of several programs at WBC focusing on the experiences of firefighter-survivors.

Leslie Kalinowski attended WBC for the first time along with her husband, Joe. She shared that “there is strength in bonding with people with similar situations in life—people who can truly understand the journey.” She explained that after attending the conference she has a new sense of “moving on” that she hasn’t had for many months. “It’s a good feeling,” she says. “I had no idea what to expect, but was pleasantly surprised. I went under the premise of being there to support Joe. I had no idea that I would take so much out of it for myself….I feel I have new resources in my journey as a spouse of an injured firefighter.”

Jeannine Barrera, wife of retired Stockton, California, Fire Capt. Oscar Barrera initially faced her husband’s injury in 1997 without this type of support. Oscar was injured when responding to a house fire during which the second floor collapsed, killing two of his fellow firefighters. Jeannine has since become a Phoenix Society SOAR (Survivors Offering Assistance in Recovery) peer supporter and a regular participant in WBC and the burn-injured firefighter spouse support group. She shares that when she was finally able to speak to other wives of burn-injured firefighters, she felt as if she had “finally found a home.”

“Before that,” she says, “I felt like I was just floating through the [WBC] conference since nothing really connected to what I went through. Yes, we all had a burn survivor connection but no one quite had the experience I had. It’s unfortunate that our support group probably will grow because that means more firefighters will be injured, but I am grateful to the Phoenix Society for understanding that there is a much needed place in their conference for the burn-injured spouse support/discussion group.”

Libby Feyh and her husband, Sacramento, California, Fire Capt. Mike Feyh, who was burned in 2010 during a house explosion that was determined to be the result of arson, have been involved since the inception of the fire service-specific support groups. Libby, who now serves as co-facilitator of the spouse support group, shares her perspective about the necessity of
having these specialized offerings at WBC and their involvement in the Phoenix Society’s SOAR program, saying: “Mike and I both went through SOAR peer supporter training a few years ago at World Burn Congress and we are proud to be part of something so important to so many. Beyond the SOAR curriculum, though, we learned that being a burn-injured firefighter, or spouse of a burn-injured firefighter, meant we had a different perspective on many things than our civilian SOAR counterparts.” For one thing, she explains, the incident surrounding a firefighter’s injury is often a media event. Additionally, the firefighter-survivor hopes for nothing more than to be able to remain in the profession that put him or her in the position of being burned.

“This creates different dynamics in the recovery process for us,” says Libby. She adds that there are many other more subtle, but nonetheless significant, distinctions that also make the experience of the firefighter-survivors and their families unique.

Libby credits the addition of dedicated fire service sessions, including the fire service-specific discussion groups, as being very helpful. There, she says, the couple could freely express their doubts, concerns, anxieties, and triumphs and know that others in the room would understand because they were walking the same road.

“This support meant a lot to us during Mike’s recovery and all through the subsequent arson-related trial and the continued glare of the media spotlight,” explains Libby. “The fact that attendance in these groups has essentially doubled each year since they have been offered is testament to their power and the need for them.”

**Firefighter-Specific Component of WBC to Continue to Provide Support**

WBC programming includes sessions that connect attendees through shared experiences and characteristics—and those addressing the needs of the fire service are now among them thanks to the efforts and participation of many. Fire Capt. Nevarez, who lost his hand and forearm after contacting a 12,000-volt power line while on a call, credits the fire service involvement in WBC with giving many firefighters “direction and the guidance to many other resources.” We hope that others in need of support will join us next year at the Phoenix Society’s 2014 World Burn Congress, October 22-25, in Anaheim, California.

Karen Badger, PhD, MSW, is an associate dean and associate professor at the College of Social Work, University of Kentucky. Phil Tammaro, FF-EMT is a professional firefighter in Billerica, Massachusetts, and 3rd district burn coordinator for the IAFF Charitable Foundation Burn Fund.

Special thanks to all those firefighters and their spouses who contributed their reflections.

---

**WBC continued from page 3**

Joe’s transformation was mirrored in the lives of other burn survivors who shared their stories throughout the week. Rob Feeney, another Station nightclub fire survivor, spoke on several panels and described how he became involved in advocacy work to help change the laws regarding sprinkler systems and fire safety in several states. Feeney was honored with the Phoenix Society’s Advocacy Award at the closing banquet. (See related story, page 5.)

**Attendees Express Gratitude for the WBC Experience**

As the conference came to a close, one burn survivor echoed the thoughts of many, saying, “Much appreciation for this week of healing and friendships. I look forward to many more WBC events.”

Perhaps a grateful parent summed it up best: “There are no words to describe the change I’ve seen in my daughter. She has become a survivor. Thank you.”

---

**GET SOCIAL WITH US!**

Facebook: [www.facebook.com/PhoenixSociety forBurnSurvivors](http://www.facebook.com/PhoenixSociety forBurnSurvivors)

Twitter: [www.twitter.com/PSburnsurvivors](http://www.twitter.com/PSburnsurvivors)

Our Blog: [psburnsurvivors.wordpress.com](http://psburnsurvivors.wordpress.com)
Feb. 4, 2007, is the day that changed the lives of Lionel and Joanna Crowther forever. A firefighter with the Winnipeg, Manitoba, Fire Department, Lionel was off duty when he got called in for an overtime shift to fight a house fire.

What was reported to be a routine attached-garage fire, proved to be anything but. Within minutes of responding to the call, a flashover occurred. Flames engulfed the entire house, trapping several firefighters on the second floor. Somehow Lionel managed to escape by jumping out of a second-story window.

When the smoke cleared and the flames were extinguished, two fire captains had been killed and four firefighters, including Lionel, were severely injured. 

Amidst the smoke and flames, Lionel saw members of his crew performing CPR to try and save their captains. Others braved the flames to gather up Lionel and carry him to the ambulance, which then rushed him to the hospital.

“It was very powerful for me to think about what these guys were willing to do to save us,” Lionel remembers.

That Fateful Knock

Joanna Crowther will never forget hearing the knock at the door that every firefighter’s wife dreads. “Even in the midst of his injury, Lionel was taking care of me,” recalls Joanna, “He asked another firefighter to call my mom so she would be the one to come to the house to tell me the news.” Another firefighter called Joanna’s brother so that she wouldn’t have to drive to the hospital by herself while her mother stayed with the couple’s two children.

Joanna had never seen a burn injury before that night and didn’t know what to expect when she saw her husband. Lionel’s first words when he saw her caught her off guard. “We should have another baby,” he said.

“I realized, in hindsight, that they had put him on some pretty good drugs,” Joanna says with a laugh. Although she was overcome with emotion in that dark moment, Lionel’s crazy remark gave her hope.

Joanna then faced the difficult challenge of telling her young sons, ages 2 and 4, what had happened to their father. How could she answer their questions when she had so many herself?

On the morning after Lionel’s injury she told the two boys, “Daddy hurt his hands at work.” But that didn’t satisfy their curiosity; they wanted to know why he couldn’t come home.
“Daddy got to ride in an ambulance and go through red lights,” she went on to explain, “without getting a ticket like Mommy did.” The memory brings both a smile and a tear as she remembers the things she did to cope in that impossible situation.

When Lionel woke up in the hospital, he had lots of questions too. He learned about his third-degree burns and that he would need skin grafts. Doctors told him it would be a lengthy recovery, but nothing in his training in the fire service prepared him for what was to follow.

“I started my fire career 16 years ago. At that time all I saw was the glory, the gear, the life of the fire hall,” remembers Lionel. In his firefighter training, there was a guidebook for almost everything. After he experienced his burn injury, Lionel and Joanna were challenged by the fact that there was no guidebook on how to recover from a life-altering burn injury.

THE HOSPITAL MEETS THE FIRE SERVICE

Joanna’s initial response to Lionel’s injury was shock. “We didn’t think this could happen to us,” she says. “Sometimes we wondered why it happened. How could it happen in our city, to our fire department?”

While Lionel suffered from the pain of his injuries, he also had doubts about his future. His hands and fingers were severely burned and he wondered if he would ever regain their use. He wondered what the boys would think when they saw him like this. Would they recognize him or would they be afraid of him? Would he ever be able to return to work as a firefighter?

Another unexpected dimension of the hospital stay was the media attention and the stream of visitors from the fire service. Lionel and Joanna were surrounded by other firefighters and their families while they were in the hospital. Sometimes their presence was healing and sometimes it was hard, especially for Joanna.

“At first I was hurt because I thought he needed them more than he needed me,” Joanna explains “but I could see the healing that occurred when he talked to his brothers in the fire service, and so I accepted it.”

Joanna recalls that at one point the hospital psychologist wanted to ask the firefighters to stop visiting so she could work with Lionel. But Joanna realized that the best form of support for her husband was to talk to other firefighters, so she allowed the visits to continue.

Eventually the hospital set aside a separate room for the fire service visits, which were often very emotional. The meeting space at the hospital became a place of healing for other firefighters and their families.

“Our department had never experienced serious injuries and death to fellow firefighters,” says Lionel. “It was new to everyone. It would have been a tremendous help to be able to talk to others who had gone through it.”

Lionel was particularly distraught that he was still in the hospital when the funerals for Capt. Harold Lessard and Capt. Thomas Nichols were held, making it impossible for him to personally attend and pay his respects. However, Joanna not only went to the funerals but played a song, at Lionel’s request, to help him say “thank you” and honor their sacrifice. “I know it was extremely hard for her and I was very moved that she was willing to do that for me,” Lionel explains.

Among the many other emotional challenges Lionel faced was the struggle with survivor’s guilt—the guilt he felt for not being able to save a fellow firefighter. He found that he needed professional help to learn to cope with his feelings.

“I had days where all I thought about was what I had lost,” Lionel says. “I needed to refocus and think about what I still have. That took some time.”

HOME FROM THE HOSPITAL

It was challenging for Joanna to both manage the boys at home and be with Lionel in the hospital, but fortunately she had help from family and friends. Then only 17 days after he was admitted, considerably sooner than the 2 months doctors had originally predicted, Lionel was released from the hospital. The couple was excited that Lionel was going home, but they weren’t prepared for what was to come.

“I went from having an entire team to care for my wounds and dressing changes and take care of every need, to having only Joanna to do all those things for me,” recalls Lionel.

It was challenging for Joanna to take care of not only her two boys, but also her husband. She felt she had to manage all of it by herself. “She was no longer my wife,” Lionel recalls, “she was my caregiver. It changed our relationship.”

Being back in his home environment also reminded Lionel of all the ways his life was not normal. He had always been a very independent person and now others had to do everything for him.

One of the hardest things was watching his brother-in-law play and wrestle with his sons because he couldn’t. “I love being a dad,” Lionel said. “My biggest fear was that I would lose my boys. They were my sidekicks. We went everywhere together.”

His limitations only made him more determined to work hard during therapy so he could reclaim his life.

FROM WIFE TO CAREGIVER – FINDING THE WAY BACK

The stress took a toll on both Lionel and Joanna. He recalls his frustration one night when he was waiting for Joanna to put cream on his burns and put his pressure garments on him so he could go to bed. As he wondered what was taking her so long, he realized that she was still busy getting the boys ready for bed. It was then he decided it was time to start doing things himself.

Lionel remembers some of his early successes, like the first time after the accident that he was able to brush his teeth on his own. After more of those little accomplishments, he started to feel like himself again. He reached the point in his recovery where the physical challenges got much easier to overcome. But as those things got easier for Lionel, it only underscored the fact that healing physically was easy when compared to recovering psychologically.

“I didn’t see it at the time, but my wife was exhausted,” Lionel recalls.

“We were on two different healing paths,” Joanna explains.
“We thought once the burns healed, life would go back to normal. But then we found that it didn’t. We had to refocus and start taking care of each other.”

“We didn’t want this event to define the rest of our lives,” Lionel adds. “We had to make a choice. Were we going to allow the tragedy to destroy our family, or would we learn from tragedy and move on? We had to make a choice and we chose family.”

**Surviving Survival**

Fortunately the Crowthers sought professional help. They saw a psychologist who specialized in helping people work through trauma. For a while things were so difficult that the couple thought about splitting up. But the psychologist taught them how to think about what the other person needed. He helped them understand the other person’s healing path.

One day the psychologist told Joanna, “You and Lionel survived that fire, but now you have to do something even harder, and that is surviving survival.”

Lionel and Joanna came to see that the were trying to act like everything was normal in a situation that was abnormal. They had to learn to redefine the roles in their relationship and learn to accept the “new normal” that comes from life after a burn injury.

For Lionel that meant going back to work as a firefighter. “It was exciting for me,” he says, “but I was only thinking about myself. I wasn’t thinking about Joanna.”

It was much harder for Joanna and the boys. Both parents had a hard time deciding how much to share with their young sons.

“It’s difficult to explain to 4-year-old why Daddy is going back to a job where he got hurt—a job that nearly killed him,” Joanna says.

**Returning to Work**

Lionel sensed that many of the other firefighters needed him to come back to help with their emotional healing. “My brothers in the fire service helped me ease back to work by being the fifth man on the truck,” he explains. Many of them wanted to see my burns because they were wondering what they would look like if this had happened to them.”

“At first when the fire alarm sounded, I was panicking every time I went out on a call,” says Lionel. “It felt like I was going to the same fire again. I knew I wasn’t completely healed. I was afraid to let other firefighters know I was scared.”

**Finding Support, Writing the Guidebook**

Lionel and Joanna have found help and inspiration through the Phoenix Society’s World Burn Congress. Just months after his injury, Lionel traveled to Vancouver, British Columbia, to attend his first World Burn Congress (WBC). He thought he was there just to gather information for others back home in Winnipeg. It didn’t take long before Lionel sought out other burn-injured firefighters to ask, “What did you do to recover? What was it like when you went back to work?” After his first WBC experience, Lionel began to talk more openly about his burn injury. He started wearing t-shirts again.

“I felt that I was proud of my scars. I accepted the fact that I survived. I made it,” Lionel proclaims. WBC has become an annual event for the Canadian firefighter, who has gone to 6 of the last 7 congresses.

Joanna, who participated in the 2013 Survivors Offering Assistance in Recovery (SOAR) Firefighter Summit and attended WBC for the first time in October with her husband, realized she was not alone when she heard other spouses talk about how a burn injury affects the entire family.

Since their recovery, Lionel, with Joanna’s support, has concentrated his studies and training on firefighter survival in its many forms. He has become a master instructor with the International Association of Fire Fighters (IAFF) Fire Ground Survival Program, a trainer for the Petzl EXO Escape System, and a SOAR-trained peer supporter with the Phoenix Society.

He now works as the district coordinator for the IAFF 13th District Burn Foundation.

“I brought my two passions together when I became the IAFF Burn Foundation district coordinator,” says Lionel. In this role, he’s writing the manual he needed and didn’t have when he was burn-injured 6 years ago. “I’m working to help other firefighters and their families so they don’t have to go through what we did all alone,” Lionel explains.

Today Lionel is proud to say he is burn survivor, firefighter, husband, and dad. In 2009 Lionel fulfilled the wish he had articulated in the first moments after his burn injury. He and Joanna became parents for a third time when their daughter was born.

Lionel carries a photo of the entire family, including all three children, in his wallet and in his heart. It’s a reminder to stay motivated and work through whatever comes his way. “This is who I’m working for. My motivation to survive and thrive didn’t come from a book or therapist or friends,” Lionel explains, “it came from being a parent.”

Joanna adds, “Now that we have gotten through the fire and learned to survive survival, our life has changed for the better.”

*Kathy Edwards is a burn survivor and member of the national advisory committee for the Phoenix Society’s SOAR program. She has conducted SOAR training workshops in several states and serves as an online chat moderator for The Phoenix Society. She is a professor of communication at Weber State University in Ogden, Utah.*
When you call the Phoenix Society, you may notice something unique in this fast-paced world of automation—you receive a warm and personal “hello” from a member of the Phoenix Society staff. And something truly special happens when a burn survivor, family member, health care professional, or fire service member calls in need of support.

Our staff of 9 people greets thousands of callers each year. Those calls are quickly connected to the most appropriate member of our program team who listens to the caller’s need and works through a course of action for each individual. Although this is just one of the many hats our program team wears in their work at Phoenix Society, it is treasured. “These calls take me back to my days as a critical care nurse and allow me to connect personally with those we are here to serve” says Pam, Phoenix Society Program Director, who has been a registered nurse for 22 years. “For so many, their phone call is their first connection to support and the beginning of a transformation.”

Maureen’s first call to the Phoenix Society in December 2012 was one of those beginnings. Maureen explained that she was burned at the age of 3 when hot oil was poured on the top of her head. However, the point she remembers really shaping her life was the first day of kindergarten in the 1950s. She arrived in class with a scarf tied over her head as she wore every day to cover her scars. It was when her teacher, unaware of her injuries, made her stand and remove her scarf that she froze in panic. Finally submitting to her teacher’s demand, she removed her scarf for the first time in public and remembers the gasps and comments that followed her as she ran down the hall to escape. Maureen, her family (including 6 siblings), and the community were unaware and unprepared to help her overcome the challenges she faced growing up with a burn injury.

For Maureen, this led to a life of isolation and constant struggle with confidence. The fear of people’s reactions kept her from taking off her wig or scarf and made it impossible to engage in daily life. She avoided experiences like getting a haircut, going swimming, or taking a walk on a windy day. It was easier to keep her scars hidden.

Fifty-seven years after her burn injury, in an effort to overcome her depression and connect with someone who could understand her feelings, she went to her local library to search the Internet for help. She searched “trauma,” then “burn trauma,” and that’s when a link to the Phoenix Society website appeared. She explored the online articles and resources with eagerness. One in particular helped “pull her out of her depression,” she recalls. “I read the Adults Burned as Children article and thought...‘this is about me, I am not alone...these feelings are normal!’ I felt validated. A weight lifted and I called the Phoenix Society the next morning.”

Something Maureen said really struck Pam during that first conversation. “I want to participate in life instead of letting it pass me by, but I don’t know how,” she remarked. That call for help was the beginning of her transformation.

“FOR SO MANY, THEIR PHONE CALL IS THEIR FIRST CONNECTION TO SUPPORT AND THE BEGINNING OF A TRANSFORMATION.”
**A PLAN OF ACTION**

Over the next year the Phoenix Society worked with physicians and social workers at the SOAR hospital closest to Maureen to further evaluate her physical scars, helped locate counseling in her local area and educate the center on the challenges of burn trauma, and walked Maureen through our online learning programs specific to empowering survivors with social skills. We also became her support system through regular emails and phone calls.

When Maureen first called, she had never met another burn survivor and “wanted to fix her burns.” After walking through the process together, she knows there is no quick fix for a burn injury but now has tools to help her live life. It has become a team effort over the last year as most of us have had the pleasure of speaking with Maureen and were all very excited to finally have the opportunity to meet her in person. With the assistance of a Phoenix Society George Pessotti WBC Attendee Scholarship, she was able to attend the 2013 World Burn Congress in Providence, Rhode Island, and for the first time meet not only the staff with whom she had been communicating, but, most importantly, hundreds of burn survivors just like her.

For Pam, meeting Maureen at World Burn Congress was particularly rewarding. “I know the courage it took for her to step out of her house and fly to Rhode Island. It is so gratifying to see her blossom, make friends, attend sessions, and be empowered to live life,” she says. Describing her experience at WBC, Maureen said, “I finally feel like I am human . . . accepted and loved.”

Looking back at the feelings of isolation she had endured throughout her life, Maureen remarked, “I wish I knew about this 57 years ago.” She encouraged other survivors to reach out, saying, “The sooner you call Phoenix Society for help, the sooner healing begins. But it’s never too late!”

**OUR GOAL FOR 2014**

Every day we receive calls from survivors like Maureen, but for every call we receive, the reality is there are thousands that have not yet connected to the resources and support they need to truly live life. In the U.S. alone, 450,000 people are treated for burn injuries each year.

The hands-on experiences of the Phoenix Society program team have made it clear that our primary need, as we move into 2014, is to reach the thousands who are still struggling alone and are unaware that the Phoenix Society is here to help them on their journey of healing. Second, we must have the staff and resources necessary to respond to the increasing number of calls we are receiving.

Your donations made Maureen’s transformation possible. Your continued support ensures we can reach survivors sooner in their recovery and be able to guide them to the support they need to overcome their struggles. What a difference you make!

**MAKE TRANSFORMATIONS POSSIBLE WITH YOUR YEAR-END GIFT**

Double Your Impact—All New and Increased Gifts Made by Year-end Will Be Matched Dollar for Dollar!

Phone calls and websites may seem to be a usual course of business, but for many of the thousands who visit our website or call our 800-line for assistance each year, it is the only connection they have to a community of support. And without it, many, such as Maureen, would continue to struggle alone in their recovery.

Having the resources to assist those who contact us is only possible with your support. By making a gift today, you are ensuring that in the upcoming year we can respond to these requests with personal assistance that will meet families wherever they are in their recovery, will walk alongside them, and will help them thrive again. Nothing heals people like other people.

Make your year-end gift today by:
- Mail – using the convenient envelope provided in this issue.
- Phone – by calling Megan Geerling at 800-888-2876.
It never occurred to Tara Stackpole that her world could be turned upside down any more than it had been on June 5, 1998. That was the day her husband, Capt. Timothy Stackpole, NYFD, was severely burn injured in a Brooklyn structure fire when he and 2 other firefighters got trapped in a collapsed building. Timothy suffered third- and fourth-degree burns over 36% of his body. One of his partners died in the fire; the other passed away a month later.

Timothy feared he might never walk again, let alone go back to work. He and his family faced a long journey of recovery, rehabilitation and coping with the many difficult stressors that follow a traumatic burn injury.

For many families in this situation, a particularly challenging source of stress is the aggressive “media storm” that often follows such an incident. “The media can be intrusive to your family life though during a difficult time like this,” Tara says. “You start to feel like your life is very exposed and sometimes out of your control.” Tara is grateful to be able to say that her family’s experience turned out to be fairly manageable, due largely to the assistance of the FDNY. The department not only provided manpower to deal with the reporters who initially “camped out” at the hospital, but it also sent others to the hospital to act as security for the Stackpoles.

Despite the daunting outlook and overwhelming new challenges, Timothy was determined to rehabilitate and get back to his regular duties at the department. Tara was at Tim’s side as often as possible, juggling hospital visits with maintaining a household and taking care of their five children.

With hard work, faith, and determination, Timothy not only achieved his goal of going back to work, but he also earned a bachelor’s degree. On December 6, 2000, his name finally came up on the captains list; in March 2001, Timothy returned to full duty at the fire department; and by early September, he had received his eagerly awaited promotion. Tim was thrilled. He loved his job more than ever. Life appeared to be getting back to normal for the Stackpole family.

Then on September 11, 2001, the unthinkable happened—the terrorist attack on the World Trade Center in New York City. Two jet airliners hit the Twin Towers. For Tara and her children, the world once again turned upside down, but much more tragically and permanently. Timothy died.

After 16 years of marriage, Tara lost the love of her life, and Kevin, Kaitlyn, Brian, Brendan, and Terence lost their dad. Their hometown was in ruins around them. One of Tara’s first thoughts amidst the shock and the dust was, “Oh, my goodness, Christmas is going to happen! How am I supposed to give my children a Christmas?” She didn’t want her children’s future to include having to tell the story about how daddy died and mommy fell apart. What follows is the story of how Tara got through the first and subsequent winters, as well as other milestones and anniversaries.

GOING INTO SURVIVAL MODE

The first Christmas, Tara went into survival mode. Her first thought was, “I need to take my kids away from all of this and just get through it.” Her family and friends swooped in and took over—and didn’t allow her to escape. Tara’s willingness to rely on others helped her make it through. She took things one step at a time. “I couldn’t even open my box of special ornaments. Every one of them had a memory attached to it. Those memories would have been a knife in my heart.” That box stayed unopened, but a couple weeks before Christmas the fire department provided a tree and new ornaments.

“My husband was a very traditional man and loved having an open door policy during holidays and on special occasions,” recalls Tara. The family decided to keep alive the spirit of celebration Tim had embodied. They also blended old and new traditions; for instance, the following Christmas they took out the old box, decorated one tree with the special ornaments and a second tree with new memories.

CREATING NEW RITUALS

Another way Tara helped her kids was to create new rituals. One of these was a holiday breakfast, originally intended for Tara’s young daughter and her girlfriends. The event grew to include Tara’s other children and their friends as well. The now-
annual tradition continues with Tara’s adult children coming home early for the holidays specifically so they can attend the “Stackpole breakfast.” Tara recalls stepping back on one of these special mornings while all the kids were filling her house with laughter and joy and thinking, “Darn, Timothy would have loved this. It’s something he would have done!” The new traditions have brought meaning back to the holidays while at the same time honoring the memory of their loved one.

Supporting Others

Tara eventually took a step that significantly improved her coping abilities. She accepted an invitation to become a Phoenix Society SOAR volunteer and got involved in a 9/11 family advisory board. The Phoenix Society for Burn Survivors SOAR program helps burn survivors and their families deal with the aftermath of a burn injury and get back to living their lives.

“When I was first asked to help as a SOAR supporter, I was hesitant because my husband was since deceased,” Tara admits, “but when I listened to what was being taught, I thought to myself, ‘I know how these patients and their families feel. I knew I could easily connect with them and help in some small way.’

Last year Tara provided support for the family of an injured firefighter from her husband’s old department. It was the week before Christmas, and she would simply go and sit with them. “The holidays were basically a wash for them, all I could do is be honest and tell them there is no one way to get through this.” When the family remembers that first difficult holiday, they will surely also remember Tara’s loving presence and the specific, powerful support that comes only from someone who has lived through it themselves.

Tara speaks of her gratitude for a psychiatrist who visited her within a week of her husband’s death. The psychiatrist told her that grief is something you never really get over, but that it lives parallel to your life, like 2 strands. Sometimes those strands lay side by side, at other times, they intersect and cause a bad day or a tough moment. He shared his best advice for dealing with those hard times: Honor them, give them the respect and space they need, and allow all the feelings that come up rather than fighting them or pushing them away. This advice, which Tara says has given her great peace and acceptance, is something she can now share with the families she supports.

Making Changes That Heal

After Tim’s death, Tara had to make certain changes in order to heal. One was to move closer to the ocean and to her family. Another was to stop feeling that she had to participate in every 9/11 ceremony and event. Instead, a private Mass is offered in her backyard every year on the evening of September 11. There is a core group of family and friends meet to celebrate Timothy’s life. Tara says the group changes and evolves, just like she and her children are evolving with Timothy gone. She recalls a particularly unforgettable year when the Mass was held during an especially brilliant sunset. Tara looked across the bay at downtown New York and saw the two spotlights from Ground Zero shooting up and through the colors of the evening. She became peaceful. She felt that Timothy was indeed there with them and realized that life does continue.

For Tara, it is not just important dates that bring hard times. “Sometimes on the less significant days I miss my husband more…the private moments and private anniversaries are sometimes harder.” They are as much a part of the fabric of her life as the happy memories.

Over the years, the most successful strategies become clear. “Do not be hard on yourself, lighten it all up. You don’t have to set out the entire Christmas village, just take a few things out. Share stories about your loved one.” Tara gets great joy from hearing one of her kids say, “Dad would have loved this.” Moments like this are a reminder that we keep our loved ones with us through our stories. She encourages others to disengage from the materialistic aspects of the holidays, not to wait for a tragedy to make it painfully clear what is really important.

For the Stackpole family, keeping Timothy’s presence alive through stories brings comfort, and the blending of old and new traditions has helped them move forward as well. Tara also feels strongly that when you’ve lost a loved one, the best way to honor them is to live your life. “That is what we can do,” she explains. “We can’t bring him back, but we can live a life he would want for us.”

James Bosch was burn injured as an infant. He has dedicated much of his professional life in 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 speaks and facilitates at burn meetings in Canada and the United States. He is a member of the Phoenix Society for Burn Survivors SOAR National Advisory Committee and a consultant.

From left to right: Kevin, Tara, Brian, Terence, Kaitlyn, and Brendan Stackpole.
18 Scholars Benefit From Phoenix Education Grants for 2013-14 Academic Year

By Maureen Kalil

Due to the generosity of our donors, a record number of 18 burn survivors are furthering their education this year with the help of a Phoenix Education Grant, or PEG. The PEG Committee, which consists of former PEG recipients, PEG donors, and Phoenix Society board members, reviews applications each summer and awards grants ranging from $500 to $3,000 for the upcoming school year.

Among this year’s recipients is a prior PEG awardee, Alexi Pyles, who is applying her PEG to the cost of continuing her studies at Bethany College, in Bethany, West Virginia, where she has declared a major in pre-physical therapy. Alexi, who is from North Hollywood, California, ultimately plans to earn a graduate degree in physical therapy or kinesiology, and give back to the community that has supported her by volunteering with youth sports, as well as programs that support young burn survivors. Alexi is active in campus athletics, breaking school records in swimming, and running cross country.

Rachel Anderson, a freshman at Lebanon Valley College in Annville, Pennsylvania, also plans to pursue a career in physical therapy. In addition to a strong academic record in high school, she excelled as an athlete in both high school lacrosse and cross country, serving as captain of both teams. That experience, she believes, provided her with strong leadership skills that will help her succeed in life. Rachel, who is from Stevens, Pennsylvania, says her goal is “to be a role model and show others that nothing can stop you.”

Like Alexi and Rachel, Logan Andres was inspired by his experience as a burn survivor in his choice of career. “As someone who has been there before, it just seems right to help others through the experience,” says Logan of his goal of becoming a psychologist. Logan is currently majoring in psychology at the University of Wisconsin–Green Bay, after which he plans to attend graduate school and, ultimately, work on a burn unit.

The fact that she will be in college at the same time as her twin has made the PEG particularly helpful to Chelsea Crawford and her family, of Montgomery, New York. Chelsea began her classes at Dominican College in Orangeburg, New York, this fall, where she is working toward fulfilling her lifelong dream of becoming a neonatal nurse.

Like Chelsea, Timothy Hatton of West Newton, Massachusetts, reports that his PEG will lighten the load of a family that will have 2 children attending college at the same time and, like Chelsea, he will use his grant to pursue a long-held dream of becoming a nurse. Timothy began work on a bachelor of science in registered nursing at Fairfield University in Fairfield, Connecticut, this fall. He wants to eventually work at the burn center where he returned for surgeries throughout his childhood. The nurses there who loved, nurtured, and cared for their patients were the inspiration for his career choice.

Connor McKemey is yet another PEG recipient who is grateful for a grant that will lighten the financial burden on a family who will have 2 children in college this year (and 3 in 2014-2015), and still faces outstanding medical bills from his injury. The Tega Cay, South Carolina, resident headed to High Point University in High Point, North Carolina, this fall. Prior to Connor’s burn injury, he was quarterback of his football team, starting center of his basketball team, and an all-star lacrosse player. Although he was able to return to the high school lacrosse field, his injuries prohibit him from competing on a collegiate level. But Connor is delighted that at High Point he will have the opportunity to stay involved in athletics through its undergraduate coaching program.

A special thanks to AlloSource, one of the nation’s largest nonprofit providers of skin, bone, and soft tissue allografts, for their recent pledge of a $250,000 donation over 10 years to the PEG program. This generous support will allow the Phoenix Society to award more scholarships each year, helping more burn survivors achieve their educational dreams.
survivors that they can face and overcome the challenges in their lives. There he would like to show young burn of adjustment and wants to eventually return as a staff member to the equipment, and certification exams required for his field of study. So the PEG Jacob received will help cover books, students, Jacob has found that the expenses of college far exceed tuition. However, Jacob is eligible for Missouri’s A+ Scholarship Program, which covers tuition for 2 years of postsecondary education. But like many students, Jacob has found that the expenses of college far exceed tuition. So the PEG Jacob received will help cover books, equipment, and certification exams required for his field of study.

John Sellem of Elk Grove, California, enrolled in Cosumnes River College in Sacramento as a part-time student this fall. After experiencing a serious injury while still in high school that left him hospitalized for a year, John became focused on school and sees attending college as a huge milestone. He plans to graduate with a degree in the psychology of adjustment and wants to eventually return as a staff member to the hospital that treated him. There he would like to show young burn survivors that they can face and overcome the challenges in their lives.

Alexandra Heyer will graduate from the University of Wisconsin—River Falls, this spring with a bachelor’s degree in agricultural business with an emphasis in dairy science. Alexandra grew up and still works on her family’s 40-cow dairy farm. She describes agriculture as a huge part of her life and her passion.

John Pennywell, also grew up on a family farm, which he says taught him the importance of fulfilling one’s responsibilities. This fall John left his Keithville, Louisiana, home to enter the Bossier City Community College paramedic program. After earning an associate’s degree, he hopes to attend the Fire Academy, and ultimately earn a bachelor’s degree in management of public utilities.

Bibiana Mondragon, of Dallas, Texas, is currently enrolled in Eastfield College in Mesquite, Texas, where she is completing her associate’s degree in social work this fall. Bibiana, who is a first-generation college student, hopes to set an example for her younger siblings that anything is possible if you set your mind to it and that hard work does pay off. She looks forward to one day helping the community in which she grew up and to reaching out to those in need as, she recalls, her family once was.

Dina Peone of Saugerties, New York, has known she wanted to be a writer since she was 12 years old. Her brother then encouraged her to consider attending Sarah Lawrence College in Bronxville, saying it was an ideal place for a writer to seek an education. Despite a serious injury and lengthy hospitalization that interrupted her high school education, Dina eventually enrolled in a 2-year program at State University of New York, Ulster, where she pursued her passion for art and writing. Last year she heeded her brother’s advice and applied to Sarah Lawrence, where she transferred in January. Dina will earn a bachelor’s degree in liberal arts there, but perhaps most importantly, she says, she will able to exchange ideas with some of the best minds in the literary world, as well as connect with agents, publishers, and internships in New York City.

Not every PEG scholar falls into the category of traditional student. While many are heading to college immediately after high school graduation, others have postponed their education. Such is the case with Dexter Durbin, who entered Mitchell Community College (MCC) in Statesville, North Carolina, only after his children had completed their own education. Dexter entered MCC planning to add a business degree to his auctioneer’s license, but soon was encouraged by faculty and fellow students to consider a teaching career. The Mooresville, North Carolina, resident is completing his studies in pre-middle grades education this fall with plans to transfer this spring to The University of North Carolina at Charlotte to earn his bachelor’s degree. Having endured more than 100 surgeries since his burn injury over 30 years ago, Dexter was awarded MCC’s James Takes Award for demonstrating incredible perseverance. On campus, he has worked to improve accessibility for students with physical challenges and established a program that provides free meals to students in need.

Elizabeth Shannon Walters, of California, Maryland, is another student pursuing an education after raising her family. In fact, she and her youngest son are both enrolled in college this year. Elizabeth, who is pursuing a dream that goes back 15 years, earned an associate’s degree in pre-nursing from the College of Southern Maryland last spring, but she faces 4 more years of education to attain her ultimate goal of

continued on page 19
Forgiveness is the ultimate resolution of unwanted loss and grief. The power of forgiveness was the theme of a talk by Fred Luskin, PhD, in a powerful session at the Phoenix Society’s 2013 World Burn Congress. A leading teacher and researcher on the topic of forgiveness, Fred also provided guidance for basic forgiving practices.

Fred acknowledged that life has so many ways to disappoint and even seriously hurt us. He explained that research and clinical examples clearly demonstrate that those who can forgive fare better both physically and emotionally than those who don’t. His discussion addressed forgiveness of self, forgiveness of others, and forgiveness of God (nature) as a helpful means of dealing with suffering and traumatic events.

During his talk, Fred covered several key points about suffering—and recognition of self in the process of suffering. Fred stressed the understanding of suffering within the human experience. “Is my suffering really unique? Or is it just my flavor?” he asked. “And don’t we all try to make our own the worst flavor? Or rather, is it really a part of the human suffering of being part of this earth?”

Fred then described the vast communication networks within the neurological systems of the brain, saying, “The survival portion of the brain (to protect yourself) is like an 8-lane super highway. Your brain is designed to make certain that any information or circumstances that are threatening to us can be delivered to the brain instantly—no matter what—to protect us.” He then explained that “the left-hemisphere of the brain is designed to keep us alive—to survive—not to keep us happy.” The “fight or flight function” is such a primitive function of the brain that other functions, such as being happy, require practice.

“However,” he explained, “the portion of the brain that provides information that makes us happy is less direct—almost a bumpy road. Therefore, we need to practice being happy. The more we practice, the more the brain recognizes that route.”

Fred led the entire group through an exercise of “quieting down” the information being processed through a set of breathing and inner focus techniques. He explained that the practice of being happy needed to be done in conjunction with quieting down the defensive communications in the brain.

“Open the pathways of good stuff,” he suggested, “flowers you stop and smell, stars that we gaze at, things that are wonderful, so your brain can grow positive pathways.”

In summary, he directed attendees to take charge of their own stories and to move from a grievance story to a story of forgiveness and the heroic choice of moving forward. He advised the audience to “put your energy into looking for another way to get your positive goals met, rather than through the experience that has hurt you. Instead of mentally replaying your hurt, seek out new ways to get what you want.”

It was a powerful session that provided motivation and hope for many Congress attendees on their journey to recovery.

Fred Luskin, PhD, teaches people all over the world to forgive. He directs the Stanford Forgiveness Projects and is the author of the best-selling Forgive for Good: A Proven Prescription for Health and Happiness (San Francisco: HarperCollins, 2002).
Fred Luskin shares the following “9 Steps to Forgiveness,” which can also be found in his best-selling book, *Forgive for Good: A Proven Prescription for Health and Happiness*:

1. Know exactly how you feel about what happened and be able to articulate what about the situation is not OK. Then, tell a couple of trusted people about your experience.

2. Make a commitment to yourself to do what you have to do to feel better. Forgiveness is for you and not for anyone else. No one else even has to know about your decision.

3. Understand your goal. Forgiveness does not necessarily mean reconciliation with the person that upset you or condoning of their action. What you are after is to find peace.

4. Get the right perspective on what is happening. Recognize that your primary distress is coming from the hurt feelings, thoughts, and physical upset you are suffering now, not what offended you or hurt you 2 minutes—or 10 years—ago.

5. At the moment you feel upset, practice stress management techniques to soothe your body’s flight or fight response.

6. Give up expecting things from other people, or your life, that they do not choose to give you. Recognize the “unenforceable rules” you have for your health or how you or other people must behave. Remind yourself that you can hope for health, love, friendship, and prosperity and work hard to get them. However, you will suffer when you demand these things occur when you do not have the power to make them happen.

7. Put your energy into looking for another way to get your positive goals met than through the experience that has hurt you. Instead of mentally replaying your hurt, seek out new ways to get what you want.

8. Remember that a life well lived is your best revenge. Instead of focusing on your wounded feelings, and thereby giving the person who caused you pain power over you, learn to look for the love, beauty, and kindness around you.

9. Amend your grievance story to remind you of the heroic choice to forgive. Move from victim to hero in the story that you tell.

In some instances, PEG recipients are using their grants to fund the graduate education necessary for their chosen career. **Elaina Meier** of Wauwatosa, Wisconsin, who is currently a high school teacher, has dreams of a career as a licensed professional counselor, working alongside clients who have a trauma history, particularly medical trauma. As a full-time student at Mount Mary College in Milwaukee, Wisconsin, she is working toward the master’s degree in clinical mental health she needs to do so.

**Jason Heard** of Iowa City, Iowa, is also pursuing a graduate education with the help of a PEG. The second-year medical student at University of Iowa Carver College of Medicine is training to become a burn and plastic surgeon. He has already authored several published research papers, presented research at several medical conferences, and traveled to Africa several times to participate in burn research, education, and prevention. Ultimately he hopes to fulfill the dream of one of his mentors and build a burn prevention and burn care training center that would serve the entire continent of Africa.

**Ashley Taylor**, who has already earned a bachelor’s degree in mathematics, is also continuing her education in graduate school in order to achieve her career goal. Ashley, of De Queen, Arkansas, is working on her master’s degree at Arkansas State University in Jonesboro. Combining her interest in math and her love of residence life, Ashley ultimately would like to be a faculty in residence—a professor who lives and teaches in a residence hall setting. While pursuing her math degrees, Ashley has gained valuable experience as a resident assistant and graduate hall director.

**Ben Olthoff** never wavered from his goal of becoming a vet. Ben graduated from Dordt College in his hometown of Sioux Center, Iowa, in May and is applying his PEG to his graduate education at Michigan State University College of Veterinary Medicine in East Lansing, which will prepare him for a career as a food animal or research veterinarian.
This list is an acknowledgement of donations and sponsorships received between May 1, 2013, and September 30, 2013. Thank you to the following individuals and organizations for their recent contributions:
The final Directions column each year is where I stop for a moment and share the impact we’ve had over the last 12 months, then focus on what we can do together in the upcoming year. The truth is I have spent the last year reflecting deeply on the impact of this organization and what burn care would look like if the work of the Phoenix Society was not present. I suppose key anniversaries tend to do that to a person!

Imagine for a moment if the Phoenix Society didn’t exist—what would your recovery, or that of those you care for, look like?

**FINDING COMMUNITY**

At World Burn Congress this year, I shared a bit about my first visit to WBC. As a new nurse, the burn center at which I was previously treated and was then working paid my way. I asked my mom to tag along with me so we could do some sightseeing in Philadelphia (when I wasn’t in a session, of course). Well, we never left the meetings. It was our first encounter with this community. As we sat with a 100 or so others hearing about their experiences, we learned that what we went through as a family all those years before were common steps to recovery. We each realized we were one of the many voices of this community and that we could add to the support offered here and learn even more than we could ever possibly give.

As the 35th anniversary year comes to a close at the Phoenix Society, I have both personal and professional gratitude for those who have helped to create this amazing safe harbor for burn recovery. I could never have imagined after my first WBC that I would one day have the opportunity to work with so many remarkable people to expand the support offered here at the Phoenix Society. I have a great appreciation and respect for the effort and intention it takes to create a safe and healing space for each of us through our cornerstone programs, such as WBC, which is highlighted in this issue.

**ONE MAN’S VISION**

All this started with just one voice who spoke up and brought others together to form the Phoenix Society. Thank you, Alan Breslau, our founder, for your vision and willingness to stand up and help create this one-of-a-kind organization. Alan knew long ago that survival was not enough. He created a place where our voices could be shared and heard by those who understand the hard truths about our experiences, as well as the triumphs we have had.

WBC has become the hub of support and education, as well as a place of healing for the entire burn community because so many are committed to the concept of this shared experience. Phoenix Society staff and key volunteers work for 2 years to bring all the pieces together for a single Congress. This program is a shining example of the power of this community and true collaboration in action. On behalf of the 873 attendees who were able to participate in this year’s program, I want to thank each and every one of you who has played a role and will continue to play a part of nurturing and growing this unbelievable place for the burn community to gather, learn, and expand burn recovery resources. WBC is where our collective voice and support is the strongest.

**RESPONDING TO THE COLLECTIVE VOICE**

The reality is that throughout the year we hear from so many of you from across the country, and the world, about the ongoing challenges you face, the pain you feel, and the resources you need to get back to life. You share with us the stories of both tragedy and of triumph. Our board of directors and staff work diligently throughout the year to have your voices heard. You have told us that we need to look at the hard truths of living with a burn injury, the social impact, and the impact trauma has on our bodies, minds, and spirits. The Phoenix Society understands that leaving these areas unaddressed—just like the burn wound that goes untreated—will hold us back from truly living. That is why we are so passionate about growing our programs and continuing to serve as a platform for your voices to be heard.

We have a history of bringing the right people around the table to address the issues that affect burn survivors and deliver quality education, programs, and resources to help you take the necessary steps to live life fully. We understand that healing does not stop when we survive a burn—it does not stop until we thrive again. Long ago you showed us the power of peer support—that learning from someone who has been there can be the first step in creating a full recovery. So we continue to build a supportive community and, with the incredible generosity of our donors, provide the resources needed to enable survivors to live a full life.
CONTINUING OUR WORK

Great work has been done over the last 35 years to build access to the people needed to help us heal, yet many still think they are alone and do not know our community of support is here for them. The week I returned from WBC, I spoke with a mother whose son was burned in August 2006. She did not know how to help her son, who was struggling at school to make it through his first full day. Her search led her to our website and the eventual call where she found help. I could hear the worry in her voice. She was dealing with so many unknowns. She was grateful to learn that there were others with whom she could express her concerns and that resources are available to help her family heal.

“I remained for 7 years in blame, pain, fear, and stress mode much like when it occurred, but to a lesser extreme.” said Lynn, mother of a burn survivor. “I stopped living. I didn’t know how to stop it. The Phoenix Society for Burn Survivors showed me another way.” However, thousands each year still do not currently have access to long-term support, but we know they will experience an amazing sense of connection once they find our community.

As we celebrate the close of our 35th year as a nonprofit organization with the primary goal of providing peer support, it has been a time to reflect on the impact we have had on burn recovery and the work yet to be done because we know nothing heals people like other people.

The Phoenix Society has been the leader in convening people passionate about helping those affected by a burn injury. So let’s all get busy on the work that needs to be done in the next 35 years! Join us by becoming an active participant in building the support community.

Regardless of why you are involved or where you are today on your path, we hope that you grow by being part of this amazing organization.

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