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Online Burn Support

Connecting with Others *Who Have Truly Been There*

By CHERYL Inmon Long, PhD



It's two a.m. and you're feeling a little apprehensive about an upcoming surgery.

You're approaching the first anniversary of your burn injury and want to share this milestone with someone who really understands.

You emptied out your closet today, throwing away t-shirts, tank tops, and bathing suits. The pain is unbearable.

You were just released from the hospital and would just like to anonymously ask someone about what to really expect.

...Where do you turn?

In 1999, it was estimated that less than 10% of burn survivors received professional assistance to deal with the emotional aspects of their injuries. Seven years later, what resources are available to burn survivors and their families facing emotional issues such as those listed above?

Increasingly, hospitals host peer support programs (such as The Phoenix Society's Survivors Offering Assistance in Recovery, or SOAR, program) where burn survivors meet in person to offer support, advocacy, and assistance. However, face-to-face groups may not always be able to consistently provide such services to all individuals. Barriers to attending these gatherings include personal responsibilities, a lack of access for those living in a rural communities, and conditions that impede mobility, including shyness or continued surgeries. Because of such barriers and the continued desire for individuals to obtain information and support, many organizations provide an Internet component to their support services.

Currently, several burn survivor organizations offer Internet burn support resources, such as listservs, bulletin boards, online chats, and opportunities to read informational articles and burn survivor profiles online. I conducted dissertation research last summer in order to examine

perceptions of Internet-based burn support resources and to explore the potential for these services to be considered a valid referral source during postburn rehabilitation. Seventy-five adult burn survivors completed questionnaires measuring coping preferences, social comfort, and social support, and answered open-ended questions about the benefits and pitfalls of online burn support.

Results of the study revealed that participants perceived satisfaction from online social support but perceived greater satisfaction from the social support they received in person, such as that provided by family members and friends. *So why log on to Internet burn support sites?*

From information obtained in the study, 100% of participants indicated that they were motivated to utilize online burn support because they "could communicate with others who truly understood or who had been there." Additionally, the majority of participants indicated that convenience (89%), anonymity (72%), not wanting to bother friends and/or family members with burn-related concerns (65%), and not having access to a local burn support group (57%) had been motivating factors for seeking support over the Internet.

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In essence, online burn support appeared to be a beneficial *supplemental* support resource for burn survivors. Many burn survivors found adequate support from family members and friends, but still sought support or practical information elsewhere that was specific to burn-related concerns.

Some participants in the study suggested that online burn support played an important part of their initial recovery. Once they came home, it was nice to be able to have somewhere to turn to for information. This makes sense because during the first year following initial hospitalization, burn survivors might be required to attend outpatient rehabilitation several hours per day and multiple times each week. They may be too fatigued to go back to the hospital and attend a group—especially if the hospital is located an hour or so away. Interestingly, even “lurkers,” individuals who read what others write without actively participating, appeared to benefit from online burn support (for example, *I go online to be more of an observer and see that there are others out there like myself...I have used them just to look and not feel alone*).

Naturally, the results of the entire research study are beyond the scope of this article. However, in order for readers to gain further insight into participants' perspectives of online burn support, I have paraphrased a few responses below under two primary areas of interest—perceived benefits of online burn support and suggestions for improvement.

Perceived beneficial aspects of online burn support:

The lack of face-to-face interaction—*Because people can't see you, you are judged on your personality and not your looks.*

Not imposing burn recovery issues onto family or friends—*I don't want to burden my family any more than they already have to be...As much as they want to, my family just doesn't understand.*

Lack of local burn support—*I wouldn't have met any other burn survivors otherwise...No one else in our community has been burned.*

It's always there—*I don't always use it, but I know it's always there...I can get information and support 24/7— it fits my schedule.*

Convenience—*My local support group is an hour drive and only meets four times a year.*

Problem-solving—*I look on the Internet for answers to personal questions I can't get anywhere else.*

Acceptance—*Even if I've been away for awhile, I am always accepted back...I realized I was accepted in the burn community even though my burns were not as severe as someone else's.*

Connecting with others after feeling alone for many years—*I realized after 30 years that there are people who feel exactly like I do, struggling with the same long-term issues that I struggle with...After 22 years, I've finally been able to associate with someone who knows the anguish, pain, and rejection of others (due to the extent of my scarring).*

Downward social comparison (finding others who have been through worse)—*Reading other survivor stories has helped me put my accident into perspective—I realized there are others dealing with worse issues.*

Support—*It's great to have burn support groups who know what you are going through...I think the online support groups are great – whether you were burned yesterday or 30 years ago, everyone has something to contribute.*

Giving support to others—*More often I go online to help others because I'm in a good place now.*

Mutual support—*It took me awhile to see that I was helping others at the same time they were helping me.*

Online support provided assistance with the process of recovery—*It helped me get ready to take the first step to ask for help in person...It helps people with facial burns build up their confidence before attending support groups in person.*

Being able to communicate with people who have “been there”—*I found that there are others out there like me...I can connect with others either by reading their profiles or by chatting—I guess it's about fitting in and, on the Internet burn survivor support group, I fit in... It helped me realize I wasn't the only one in the world that feels the way I do...You can open up to these people more than anyone else—after all, they have been there.*

Caveats and ideas for improvement

Supplemental support—*I believe that people online should be encouraged to eventually move beyond the chat room to the public arena...This can't be the only source of support.*

Moderated chats—*We get off topic a lot—more moderation would be nice...More moderated chats—sometimes I ask questions or share something but there are*

other conversations in the room and my questions remain unanswered.

Let others know—*Make it more known—I found it 6 years after my injury.*

Remind participants to seek medical advice from their doctors—*Participants should be reminded to check with their own doctor before trying some of the suggestions...Some go beyond the role of a peer and give professional advice that they are maybe not qualified to give.*

Additional chat times—*More European-friendly times.*

Increased information—*Have both professional participation and peer-based information.*

Photographs—*More pictures—I think pictures help everybody desensitize themselves regarding scars.*

Advertising—*Let doctors and hospitals all around the world know about online support so they can tell people...Post a notice in burn units to let people know that there is help out there from peers who have suffered this kind of injury...The hospitals need to give out a list of the websites...Provide notice of online support in physicians' offices.*

Outcome literature on postburn psychosocial adjustment, albeit limited, has presented contradictory information. Some research studies tell us that burn survivors are extremely resilient, that individuals have described the positive impact the injury had for them, and it helped them to put things into perspective, as they express a desire to use the experience to help others. On the contrary, other studies have suggested that many individuals experience significant difficulties, such as depression, post-traumatic stress, and social anxiety.

For individuals who would benefit from postburn psychosocial assistance, burn scholars, burn care professionals, and burn support organizations are actively working to develop and provide effective programs to address such needs. However, many individuals in burn intensive care units today will be released from the hospital without the necessary knowledge and skills to tackle difficult social encounters and post-traumatic stress, which occur for some individuals each and every day.

Because adequate face-to-face burn support services are currently lacking, burn professionals may wish to consider referring burn patients to online burn support as a supplemental referral resource for information and support during postburn rehabilitation. Because the first year of physical burn rehabilitation is intense, time-consuming, and crucial to future mobility, it may be especially beneficial for patients to know about online burn support upon being discharged from initial hospitalization, even if face-to-face burn support services are available. Whether individuals are new to the burn survivor population or they are veteran burn survivors, they might find online burn support to be a convenient resource where experiences can be shared within a community of individuals who truly understand, during any time of the day or night, because unlike many of us, they have *been there*.

Cheryl Inmon Long, PhD, is a school psychologist in North Texas. She completed a doctoral degree in counseling psychology from Texas Woman's University. Her dissertation research was presented at the 38th Annual Meeting of the American Burn Association in April 2006. Her daughter Meredith is a burn survivor.

www.phoenix-society.org

***Join Us Each Wednesday 8:00–9:30 pm (EST)
for an Online Chat Session***

Share information and support with members of the burn community from across the country through online chats. Phoenix Society chat sessions are moderated by SOAR-trained volunteers.

To be able to join a chat, “Add Your Story” in the “Community” section of the website anytime.

You will receive a user name and password for accessing future chat sessions.

If you have questions or need assistance, call 800-888-2876.

Partnering to Build Better Resources

BY AMY ACTON, RN, BSN

Power in organizations is the capacity generated by relationships.

Margaret Wheatly

As I write this, we are in full swing preparing for World Burn Congress (WBC) 2006. This year's planning committee has worked diligently with a shared vision to provide a safe and healing environment for those affected by a burn trauma. Our goal of maintaining a quality, affordable program requires a huge effort that would be impossible without the partnerships we have with our hosts, volunteers, organizations, and sponsors. Our three WBC hosts, Shriners Hospitals for Children Northern California, University of California Davis Medical Center Burn Center and Firefighters Burn Institute, have been working extremely hard with our Society staff to do so. In addition to their support, other burn-related nonprofits, hospitals, fire service organizations, corporations, and individuals have contributed toward the effort to provide a national forum where burn survivors, their families, health care providers, and the fire service can come together to learn about burn recovery. We now serve more than 675 attendees each year and we know it goes way beyond the numbers—WBC is often a life-changing experience for attendees.

We continue to look for creative ways to partner with more organizations to expand access to WBC and address other needs of the community. While the Society's most visible partnerships may be with those groups supporting WBC and SOAR (Survivors Offering Assistance in Recovery), we continue to explore such relationships to enhance resources for burn recovery.

An exciting, new example of partnering to build better resources is "The Journey Back" project. The Phoenix Society identified a need in the burn community for access to school reentry resources. We often receive calls from teachers, parents and health care providers looking for resources to help a child or adolescent return to school immediately after a burn injury or at a time later in their life when a transition occurs. The Journey Back resources have been developed to supplement programs that are currently providing back-to-school support and provide a framework for those who don't have access to school reentry services. As we contacted groups to gather input and content ideas, we found that many organizations, even those who already had a school

reentry program, were excited about our effort. Some reported that, while they provided school reentry assistance, their program had not been formalized and often was redeveloped whenever there was a change in staff. This only reinforced our goal—to develop a quality school reentry resource that could be used by any caring adult to assist in this critical adjustment for a burn-injured student.

As we shared our vision about this project, many who had partnered with us in the past wanted to be involved by providing expertise and financial support. Mary Werderitch, the Executive Director of the Illinois Fire Safety Alliance (IFSA), and her team were considering a similar statewide project and came to the conclusion that by supporting our efforts, we could create a strong national resource that would reach out to thousands of children and adolescents and supplement their statewide efforts. The IFSA became our first Diamond Level Partner for this project, and were later joined by four other funding partners to date, Firefighters Burn Institute, Firefighters Quest for Burn Survivors, Children's Burn Foundation and the Blodgett Foundation. We are continuing to reach out to those who would like to partner with us in ensuring that anyone caring for a burn-injured child or adolescent has access to school reentry resources when they need them. We are over halfway in raising the necessary funds to complete this important resource. With adequate funding, it will be provided on-line for free by the spring of 2007.

More people in need of support have access to quality resources and programs because of these types of partnerships. The combined knowledge, support, and connections that everyone brings to the table helps expand the reach to those in need. Sometimes we think it is easier to do it ourselves—or we strive to be the sole provider of a resource or program. In some cases this may work and may actually be necessary but the reality is resources are limited, the need is great, and no one can "do it all *all* the time." Working together does demand open honest communication, clear goals, a shared vision, and a dose of patience, compromise, and mutual respect but it is all worth it! As we reach out and expand our partnerships we are learning how to do all of the above a little better every day as an organization.

A Word from Our “Diamond Level” Sponsor

IFSA Gets On Board “The Journey Back”

BY MARY WERDERITCH
EXECUTIVE DIRECTOR, ILLINOIS FIRE SAFETY ALLIANCE

The Illinois Fire Safety Alliance (IFSA) is thrilled to partner with The Phoenix Society in its very worthwhile programs. We are especially proud to be a part of “The Journey Back” school reentry resource that is being introduced at this year’s World Burn Congress. The IFSA believes that by working together we can develop strong resources to assist burn survivors within our community and beyond. Our plan is to utilize “The Journey Back” to assist children throughout our state reenter their school environment with confidence.

About IFSA

The purpose of the IFSA is to bring together persons or groups with a common interest in fire safety, burn prevention, and public education, and to promote programs and disseminate information related to fire safety and burn prevention. We continue to add new prevention programs that will be made available to the fire service, schools and the private sector in Illinois. Other programs of the IFSA include the following:

IFSA “I AM ME” Burn Camp—It is Camp “I Am Me” that is our constant reminder we need to continue our mission of disseminating fire safety and burn prevention materials. The camp, which is held the third week of June every summer, was attended by 95 children in 2006.

World Burn Congress Scholarships—Each year we have sent at least three burn survivors to WBC and this year we are excited to assist by volunteering for the event, where we will assist with closing banquet seating.

“Too Hot for Tots”—Our organization provides every hospital with a maternity unit in Illinois with bath thermometers, now known as bath buddies, a scald prevention tool. Our goal with the distribution of these thermometers is to raise the burn awareness level to help decrease the number of scald burns that continue to occur annually in Illinois. We’ve changed the design so that they can also be used in our older adult population.

Get Fired Up About Fire Safety—This program currently in development is a fire safety and burn prevention curriculum for preschool, primary, and intermediate levels with interactive activities as well as pages that can be printed out. We are very excited about the development of the CD and hope to be able to provide them to our educators, fire service, and private sector in the near future.

Home Fire and Burn Prevention Guide—These guides have been very well received in Illinois. If you are planning an open house, teaching fire safety, etc., please give our office a call to place your order. There is no cost and they are available in both English and Spanish. The public educators in Illinois have told us that this is the most all-encompassing guide available in our state.

Newspapers in Education—The *Chicago Sun-Times*, the Illinois Fire Safety Alliance, and ComEd have partnered and developed a program that teaches children about fire safety and burn prevention. As a team, an eight-page section is created every year and included in the *Chicago Sun-Times* newspaper every Tuesday during the month of October. The paper is distributed to every fourth grade student in Illinois as well as in every edition of their paper.

State Fair—Each year we man the fire safety tent at the Illinois state fair. If you live in Illinois and want to volunteer, give us a call. No experience is required and Explorer Groups are welcome.

Fireworks—An informative fireworks CD has been developed and was sent to every fire department in Illinois. The CD clearly shows the dangers of sparklers to children and adults. Our organization is seeing more and more children at our burn camp that have suffered serious injuries from just a moment’s touch of the tip of a sparkler.

Please visit our website at www.ifsfa.org to learn about upcoming IFSA events and new new programs.

We encourage other organizations to get involved in “The Journey Back” school reentry resource. Join the team effort required to make a difference!

Having Fun While Helping Others

BY AMY ACTON, RN, BSN

It's been a busy start to the summer season for friends of The Phoenix Society. Throughout the country, activities and events have raised funds and increased awareness of the Society's programs.

What else happened? Lots of fun!

An Amazing Race

In early May the third annual "family and friends" weekend at Sharon and George Everett's home kicked off the season. Sharon, George, and their family assembled 20 runners again this year to participate in the annual Flying Pig Marathon and Relay Race in Cincinnati, Ohio. After encouraging two 5kers, six relay teams, and two marathoners to run for the Society, they set out to secure pledges—this year raising more than \$12,500 to support Phoenix Society programs. But George did more than solicit donations—at 58 years of age, he ran his second marathon and, to my amazement, he had a smile on his face in every picture of him I have seen from that day. George was very proud that his entire family, and many of their friends, joined them this year to support their goal of helping others who may need the assistance of the Society. George and Sharon are well aware of the value of such support. Since Sharon was burned 6 years ago, George explained, the whole Everett family has benefited from World Burn Congress (WBC) and other Society resources.



"TEAM EVERETT" AT THE FLYING PIG MARATHON

George hopes to inspire others across the country to join in this effort to run, walk, or bike for the Society. It really is easy, he said, explaining that all it really takes is a desire to get moving and help others. And move he did! George ran 26.2 miles in 4 hours and 38 minutes—a 23-minute improvement over his first marathon 2 years ago.

A Weekend of Wheels

The West Michigan Burn Survivor Car Show and Buses by the Beach participants joined together in late May to show off their wheels, do some camping, and raise some serious dollars for burn survivors and their families.

It all started with the 10th West Michigan Annual Burn Survivor Car Show and Auction. John Merryman, who has chaired this event since its beginning, and his team of dedicated volunteers put on another fun show that included the West Michigan Fire Service, monster trucks, and participation by every branch of the U.S. Military. The group's goal is to assist burn survivors after they leave the hospital setting and they have done so by raising more than \$150,000 over the past 10 years to support the local burn center and The Phoenix Society. But their efforts don't stop with the car show, several members of the car show team now also volunteer annually at WBC, where you may have met them manning the registration desk.

Several years ago the annual car show provided the inspiration for a related fundraiser when burn survivor Brien



WESTERN MICHIGAN BURN SURVIVOR CAR SHOW



BRIEN DEWS SELLING T-SHIRTS AT BUSES BY THE BEACH.

Dews had a chance meeting in his clock shop with Todd Olson and discovered that they both had a passion for Volkswagen buses. Todd also mentioned his desire to come up with a way to raise funds for a charity with a campout for VW buses. To make a long story short, Brien invited Todd to the burn survivor car show and soon after they started planning an annual camping event for the same weekend as the car show. In the 4 years since, they have raised more than \$30,000.

This year 53 VW buses and cars from across the U.S. and Canada participated, taking home the “most cars” (or, in this case, buses) award at the car show, even beating out the ever-popular Mustangs. After the show, the VW enthusiasts returned to their campout where they raise funds by selling t-shirts and holding a raffle.

In addition, the campground donates a portion of the site fees and Todd Olsen’s employer, XTRA Lease Corporation Charitable Foundation, matches the funds raised. This year’s Buses by the Beach volunteers raised more than \$10,000, all while camping, enjoying music, and eating great food.

A Night to Remember

That same weekend in May a group of Phoenix Society members in Massachusetts danced the night away at yet another fun fundraiser. George Pessotti and his volunteer team of friends and support group members were joined by burn survivors from Massachusetts, New Hampshire, and Rhode Island at the group’s 6th Annual Spring Dance.

Platinum sponsors Swartz, McKenna & Lynch of Boston again donated \$10,000 toward the effort this year and an



HERB BAYRD AND JOSEPHINE FARLEY AT THE MASSACHUSETTS SPRING DANCE.

additional \$8,000 was raised with a silent auction and raffle. This dance is just one of many events that the New England group holds to raise funds for WBC scholarships and provide direct support for other Phoenix Society programs

This dedicated group continues their fundraising efforts in October, when they are getting together again for their first Walk for Burns Event, so if you are in the area, please consider joining them. (Watch the Phoenix Society website for details.) I promise you will have fun while supporting programs that affect the lives of many burn survivors and their families.

More Than Dollars and Cents

The Phoenix Society is incredibly fortunate to have the support of such dedicated members and their friends. The funds raised from these events will help so many other burn survivors and families with the recovery process. But the true impact of these efforts goes way beyond the dollars raised. *These events are the result of our own community working together and sharing a vision to help others.* These survivors, who have transcended their burn injuries and are able to give back to others, send such a powerful message of hope, perseverance, inspiration, and love and show you can have fun while doing it!

To learn more about how you can join The Phoenix Society for Burn Survivors “team” and walk, run, or bike for burn survivors or support The Phoenix Society through another fundraising effort, call the Society office at 800-888-2876.



THE PHOENIX SOCIETY
FOR BURN SURVIVORS, INC.

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The Phoenix Society for Burn Survivors

will be showcasing our newest
resource at this year's
WORLD BURN CONGRESS.

"The Journey Back, *Resources to assist school reentry after burn injury.*

is a wealth of information for the parent, health care provider, teacher, or caring adult in the student's life. Information on preparing, supporting, presenting, and evaluating school reentry are all included. A DVD with examples of key points and messages are included along with CD-ROMS loaded with resource information.

**This resource is suitable
for the beginner or
seasoned presenter.**

Thank you to our
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toward* we continue to
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Burned, But Not Necessarily Depressed

BY PATRICIA BLAKENEY, PhD, AND WALTER J. MEYER, III, MD

People who do not know burn survivors typically believe that anyone who has experienced a severe burn injury will be depressed. They also usually believe that people who have burn scars or other physical changes as a result of their burns will be depressed as a matter of natural order.

However, anyone who has ever attended a camp for burn survivors or a World Burn Congress knows that depression is not a necessary reaction to burn injury. Actually, the best estimates indicate that less than half of burn survivors will suffer moderate or severe depression after the second year following their burn injury. Their depression, of course, may have nothing to do with the burn injury. In fact, the best predictor of which survivors will become depressed is whether they suffered from depression before they were burned. Beyond that, studies indicate that women survivors, like women in the general population, are more prone to depression; and one study¹ found that women with burns of the face and neck were particularly apt to become depressed. But, when reading such studies, it is important to ask how the investigators defined and measured depression because studies vary widely; the best studies will provide that information.

What Is Depression?

It is part of our culture that people expect to feel “good” or “happy”; when they feel otherwise, people are likely to decide they are “depressed.” However, they may be sad and grieving following an important loss. They may be angry and unable to accept or express their anger; in one study we conducted of teenaged burn survivors, we found that anger was a typical distressing feeling rather than depression. Some people say they feel depressed to describe a temporary feeling of a few days. To be diagnosed with major depression, a person must have *five or more* of the following symptoms *for a period of at least 2 weeks*, and the symptoms must represent a change from previous functioning:

- Depressed mood most of the day (may be an irritable mood in children and adolescents)
- Noticeably diminished interest or pleasure in most activities
- Significant change in appetite, resulting in either weight loss (without dieting) or gain (for children, failure to make expected weight gains)

- Inability to sleep or sleeping too much
- Feelings of worthlessness or excessive/inappropriate guilt nearly every day
- Fatigue or loss of energy nearly every day
- Difficulty concentrating or unable to make decisions nearly every day
- Noticeable difficulty sitting still or very slow reaction and movement
- Recurrent thoughts of death (not just fear of dying), thinking about suicide, attempting suicide, or planning to kill oneself

Severity of depression depends on both the number of symptoms and to what degree the symptoms interfere with the person’s life at work, socially, and in relationships. For example, the diagnosis is mild depression if the person has few symptoms (beyond the necessary five) that cause only minor difficulties in the person’s work, usual social activities, or relationships with others. If the person has many symptoms and if the symptoms cause significant difficulty for the person at work or socially, the depression is considered to be *severe*.

Are Burn Survivors More Vulnerable to Depression?

There are many reasons to believe that burn survivors are more vulnerable than the general population to depression. First, the statistics suggest more frequent occurrence among burn survivors; although there is wide variability among findings in studies of burn survivors, most report rates of depression to be between 40 and 50%. In comparison, the American Psychiatric Association estimates the percentages of people in the general population who will become depressed ever within their lifetimes are 5-12% for men and 10-25% for women.² However, the statistics are only one reason to believe in the greater vulnerability of burn survivors; there are others, beginning with what we know about what causes major depression.

What Causes Depression?

Recent animal and human studies (within the last 20 years) indicate that hormones produced as part of the body’s response to stress also give rise to depression, and stress seems

to play the most important role in initiating major depression. One study³ identified the following four factors that contribute to vulnerability to major depression and ranked them in descending order of importance of contribution:

1. Stressful life events
2. Genetic factors
3. Previous history of major depression
4. Neuroticism

A second study⁴ compared a group of individuals with major depression to a “control” group without major depression to determine whether stress seemed to cause major depression and whether it mattered if the stress was a stressful life event or chronic stress, such as ongoing worry about daily life. Stressful life events seem to be the critical factor, for there was no difference between the two groups in terms of chronic stress. Some of these individuals probably were suffering from posttraumatic stress disorders (PTSD) also; symptoms of PTSD overlap with depression in many respects, and similar medications are used for both conditions

Also, for the depressed group in the study, significant life events occurred with the first two depressive episodes with significantly higher frequency than with later episodes or with the nondepressed group. Persons who were having their third or later episode of major depression had no more life events than controls.

It seems that stress associated with a significant life event sets off the depressive reaction only in the early occurrences of a person’s major depression, but after the first two occurrences, the person is likely to become depressed without such a trigger event, as if the body has learned (without the person’s knowledge) to respond by becoming depressed. It would be with these later episodes presumably that genetics and temperament play important roles.

Stress of a Severe Burn

Everyone who has had a burn injury that required hospitalization has had a significant stressful life experience, and virtually everyone who has survived a severe burn injury has experienced physiological stress with its associated hormones. For people with massive burn injuries of 40% or more of their bodies, the stress response is prolonged, lasting for up to 2 years. During the time that the body is still involved in the stress response, the person will feel easily fatigued, have difficulty concentrating, probably have disturbed sleep, etc.; in other words, the person will have many symptoms of major depression.

People with burn injuries also suffer loss. This loss could be body appearance and/or body parts. Sometimes it is loss

of property and loved ones in the fire. Grieving for such losses can also cause the same symptoms as depression, such as disturbed sleep, anxiety, labile emotions, depressed mood, and crying spells. The grieving process usually lasts less than 6 months but in some individuals can last up to a year or more. If it lasts 6 months, it should probably be treated with medication as you would a major depression.

Several studies of burn patients have shown that pain levels can predict rates of depression. In general, the more depressed patients are, the more pain they tend to report; and the more pain they report, the more likely they are to be depressed. And everyone who has been treated for severe burns has experienced pain. In fact, in some cultures and individuals depression is expressed as somatic symptoms of chronic aches and pains, such as chronic headaches or pain in the liver.

Without even considering the multitude of psychological, physical, and social challenges that burn survivors must face in the course of their recoveries and rehabilitation, it is easy to imagine that burn survivors may be more prone to depression than people who have not had similar experiences. In fact, it seems remarkable that the rates of major depression among burn survivors are not higher than those that have been reported.

Getting Treatment

No one in the United States has to suffer from major depression if they can afford, either through public or private means, a doctor’s visit and a prescription. The documented cost to society of untreated major depression (second only to heart disease) is such that government-funded public mental health clinics offer psychopharmacological treatments to most adults. There are many good courses and articles written for primary care physicians about the diagnosis and treatment of depression, and most are willing to assist a depressed patient. Some very good and safe medications such as fluoxetine (Prozac[®]) are now generic and cost literally a few cents a day. Many of the medications that have come on the market since 1985 are very safe. Someone who does not respond to one will often respond to another. The barriers to treatment seem to be cultural and psychological (that is, an unwillingness to acknowledge the depression and ask for help), rather than financial limitations or an unavailability of competent and qualified helpers. As is always the case, the first step in getting help is to acknowledge and accept the problem, perhaps by listing all the perfectly acceptable reasons for being vulnerable to depression and remembering that most of those reasons are outside the individual’s control. Thus, one need not feel guilty for being depressed. *And no*

one, even a psychiatrist, should ever treat their own major depression, so asking for help of a qualified person is the most intelligent action to be taken.

Psychological or Biological Treatment: Is One Better?

A very careful study sponsored by the National Institute of Mental Health (NIMH)⁵ addressed this question by comparing the success rates of psychotherapy vs. placebo vs. antidepressant drug therapy in the treatment of major depression, and found that, *for severely depressed and functionally impaired persons* (refer to the definition of severe depression on page 9), antidepressant drug is highly effective but should be given for at least 6-12 months, or even longer, to prevent relapse. The authors also state strongly that frequent, supportive counseling (very much like some forms of psychotherapy) that focuses on the immediate problems of the individual should be provided along with the medicine. In this study, patients in all treatments, even placebo, showed significant reduction in depressive symptoms and improvement in functioning over the course of treatment. In general, a combination of medication and psychotherapy provides the best treatment.

“... the best predictor of which survivors will become depressed is whether they suffered from depression before they were burned.”

In summary, antidepressant medicines, and there are many for the physician to choose from, are extremely effective. However, especially in the beginning of treatment when the beneficial effects of the medicines are not yet noticeable to the depressed person, it is important to also have some form of counseling or psychotherapy to encourage the person to maintain hope, assist in handling immediate problems, and help the person learn to think in new ways that do not continue the old “depressive” and “hopeless” patterns of thought that deepen depression. Several studies have concluded that a combination of antidepressant medicines and psychotherapy is more effective than either alone. As the symptoms of depression recede, the tendencies toward hopelessness and negative thinking also seem to recede, making it easier for the individual to practice new, more optimistic ways of thinking that are developed during psychotherapy.

What kind of psychotherapy is best?

Studies of the effectiveness of various approaches to psychotherapy for depressed persons are often contradictory

and confusing. They refer to types of therapy, such as “cognitive behavioral therapy” or “interpersonal therapy” or “psychoanalytic psychotherapy,” as if they were each a pure and distinct specimen that could be easily recognized by the observer or participant. For purposes of studies, the therapists involved probably do attempt with some rigor to hold to strict guidelines; however, in practicality these terms often imply more about how the therapist understands human behavior than about what actually happens in the relationship between the therapist and client. The outcomes studies do seem to agree that, for depressed persons, therapy that is focused on the present time and current problems, on correcting current dysfunctional attitudes and thinking, and on managing current stressors is more effective than therapy that addresses unconscious determinants of behavior and historical phenomena.

Helpful additions to medicine and individual psychotherapy

We have been talking about individual treatment, but group therapy and family therapy can be useful additions in treatment of depression. Groups not only allow the individual to experience his/her “sameness” and shared difficulties with others (thus decreasing the isolation often developed by depressed persons), but also allow the practice of new behaviors and trying out new ways of thinking in a safe environment. Family therapy can assist members of the family cope with the difficulties of living with a depressed person and can also address behaviors of family members that support and reinforce the negative patterns contributing to depression.

Another addition to treatment of depression that seems to be quite helpful is physical exercise. It may seem unusual to think of exercise as a “treatment” but several studies emphasize the importance of moderate exercise in the treatment of depression. Physiological studies demonstrate that exercise alters brain chemistry in ways that suggest decreased depression would result, but studies of such a direct relationship are as yet inconclusive. What does seem clear is that an exercise program that matches the physical capacities of the individual would be a worthwhile addition to a treatment program for the depressed individual, whether because of altered brain chemistry or simply the feeling of accomplishment following successfully completing a day’s physical activity.

Helping Yourself

Helping yourself is not a substitute for treatment; if you have even a mild major depression or if you even think you

might have a mild major depression, or if others think you might, the most intelligent thing to do is see your doctor and ask for help. Even if you are just feeling blue, but it happens too often and is affecting the way you work or relate to others, see your doctor. However, there are things to do that can help you feel better even when asking for help or while you are waiting for treatment to begin. These same things can help you feel better faster after you start treatment. And, if you are not really depressed but are sad or blue or feeling a little down on yourself, some of these same ideas can help you end the day feeling better and more optimistic about tomorrow.

Have hope...for a happier tomorrow, for a friendly smile, for something good to happen. Most people who are depressed and who involve themselves in treatment do very well even within the relatively short span of 4 months.

Do not dwell on all the negative things in your life and do not persist in reviewing past events and past actions, especially after the third or fourth time you have gone over them and found yourself lacking in adequacy. Studies have found that, among people who have experienced the same stressful life event, those who become depressed differ from those who do not by thinking about the event and outcome and their actions over and over and over.^{6,7} Think about those things once or twice, and ask yourself what you could have done differently that would truly have been better. If you have an answer for that, then you have learned a lesson and that is good. Feel good about that.

“No one in the United States has to suffer from major depression if they can afford, either through public or private means, a doctor’s visit and a prescription.”

If you do not have an answer, then **work at stopping the thoughts**. First become aware that you are having the thoughts; when you begin to have them, remind yourself that you do not have to continue. You already know how they are going to go, and you already know the end point, so you might as well think about something new. If you decide you must have those thoughts, set aside a 20-minute period later in the day, and have them at that time.

Be patient with yourself. There were good reasons that you learned whatever negative thinking and feelings you are having, even if you do not know what those reasons were. That means that they served a purpose at the time you began them. They seemed helpful or protective in some way, so you repeated the pattern many, many times until it has now been well learned. Learning new ways of thinking and new

behaviors will also require practice, and you will, at first, find those negative thoughts just popping into your head as if they are out of your control. This is normal; do not scold yourself. Know that changing is hard work but will become easier with practice. Eventually, positive thoughts will occur just as readily.

Think of all the different roles you play and how you are valuable in each role. Most of us have many roles; perhaps you are a wife, a mother, a teacher, a daughter, a friend, a sister, and so on. What value do you have and to whom in each role? Write these down, so that when you begin those negative thoughts that say you are a failure, you can be more realistic in thinking about yourself. Perhaps those “failure” thoughts began with your daughter’s tears while she complained that you never have enough time to do what she wants you to do. You disappointed your daughter at that moment, but that does not make you a failure as a wife, a teacher, a daughter, etc. Perhaps there were other events in the same day that actually indicate you were superb as a wife and as a friend.

Devote as much time to thinking about positive accomplishments and imagining positive outcomes as you do about negatives. Have you spent 15 minutes dwelling on negatives? Now spend 15 minutes with positives.

At the end of each day, ask yourself, and make yourself answer, “What was the best thing that happened for me today?” It doesn’t have to be startling or even very good; if you really believe that only bad things happened, then choose the best of all those bad things. Also ask yourself to name one thing you accomplished during the day, even a tiny thing.

Set achievable goals and reward yourself when you accomplish each one. Break big tasks into little steps and reward yourself for accomplishing each step.

Move your body. Moderate exercise is helpful, but even walking around a room or changing your environment by moving from one room to another can help. Go out to a movie or a ballgame or some activity where you will not feel challenged. If you are a burn survivor who does not want to deal with other people’s reactions to your scars, ask someone you trust to go with you and, for this occasion only, to take responsibility for handling any staring, rude comments, and questions about your appearance. You can go just to enjoy the event.

Be patient with yourself. This should be noted twice or more often. Feeling better occurs over time, little by little.

Take breaks, take mini-vacations (like a day away from solving problems or dealing with important matters), and get enough rest. When you are depressed, you feel fatigued even when you think you have had enough

rest. However, be sure you are sleeping enough to be well rested. If you are unsure, ask your doctor.

Spend time with people you can talk to and laugh with. Listen to their ideas about things you worry about. You have heard your own ideas about your worries way too often. There is no sense in telling yourself the same things over and over again. Get a new point of view.

Specifically for Burn Survivors

When you begin looking for treatment or begin talking with a new doctor, be assertive about what you want help for. Sometimes your concerns do relate to your burn injury and burn scars, but not always. You are many things beyond your burn, and not everything in your life is related to burns and burn scars. We have too often heard stories of burn survivors who sought help and found that the helping professional, unfamiliar with burns, kept focusing on problems related to the trauma of the injury and to the difficulties of living with scars while the unhappy survivor wanted help with marriage or death of a parent. Tell the helper clearly what you want help with and, if the helper continues to focus on something else, find a new helper.

Final Thoughts

The most important conclusion to be drawn from all of this information is that if you are feeling sad or blue or depressed so often that you are having trouble getting important things done or relating to your family and friends, talk to a doctor quickly. Depression perpetuates more depression. Once an individual becomes depressed there is a tendency for that person to isolate himself or herself socially, to quit taking care of basic health and hygiene, and to avoid daily work and home tasks. This pattern adds to the depressed person's feelings of hopelessness and helplessness. Soon, everything can seem overwhelming, and depression is deepened and prolonged. It is important to avoid such a process as soon as possible. Every effort should be made to encourage and support the depressed individual in maintaining the essential activities of normal life.

Do not worry about whether your bad feelings really mean you qualify for the diagnosis of major depression. Unfortunately there is no diagnostic category in psychiatry and psychology for ordinary human misery, and such misery commonly produces some symptoms of depression. The same treatments can help with the symptoms of depression, and if you have any symptoms, treatment of some sort is available and important.

Successful treatment that guards against future depression will probably include an antidepressant medication, but it will not stop there. It is easy for an individual in our society to

hope and even believe that taking a pill will solve their anguish. However, successful treatment for the long haul will also involve the depressed individual doing some hard work with the help and encouragement of others, hopefully including a counselor or psychotherapist who may be the same doctor that prescribes the medicine.

Never believe that because a person has been burned, that person should also expect to be depressed. Depression is not necessary. Depression is treatable. There is no need to suffer. Individuals with scars and amputations from burn injuries are able to find ways to use their bodies to achieve their goals without being intimidated by physical limitations. It is equally true that they can live their lives without being limited by expectations and attitudes of others. And it is true that the most difficult challenge of all is to overcome the limitations of one's own expectations, social perceptions, familiar behaviors, and psychological patterns. However, the work of change can be fun...and it can be as important in saving the life of the depressed burn survivor as the antibiotics and surgeries that saved the physical life.

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12-Year-Old Jack Sample Tries to “Live Each Day to the Fullest”

BY NICOLE E. SMITH

In some ways, Jack Sample is your average 12-year-old boy. He likes to go to the beach, to hang out with his friends, and to listen to music. He enjoys school and traveling, and wants to be a movie director when he grows up.

But what sets Jack apart from other boys his age is that, in many ways, he has already found some answers to the age-old question, “What is the meaning of life?”

Costa Mesa, California—On December 19, 2002, Jack, who was 8 at the time, and his younger brother, Clayton, who was 6, were staying at their grandmother’s house while their dad, Tim, was at work, and their mom, Piper, was running some Christmas errands. Jack and Clayton were playing in the dining room, when Jack decided to investigate a lit candle. Before Jack knew what was happening, the candle accidentally fell on his shirt, quickly catching it on fire.

Lis Sample heard her grandsons’ yelling and ran into the room. She rolled Jack on the ground and instructed Clayton to call 911.

Shortly after, Piper received a phone call from her mother-in-law informing her that Jack had been burned. Piper quickly jumped into her car and raced to the house. Initially, Piper said she didn’t think much of it, but on the way over, she said she started to get scared.

As she approached the house, her fears were only compounded. Firefighters and paramedics were on the scene. A firefighter stopped her on her way into the house to attempt to prepare her for the situation. At that point, all Piper said she understood was that her son was inside screaming, and she knew she needed to be with him.

Looking back, Piper described it as a “surreal feeling.” She said, “I had no idea what to expect, but I knew I had to pull it together and be with my son.”

Jack was transported by ambulance to the burn center at the University of California at Irvine (UCI). During the ambulance ride, Piper said she tried to reassure Jack and to keep him calm. She said, “I kept telling him to look into my eyes and stay with me.” Jack said he remembers being loaded into the ambulance, but doesn’t remember getting to the hospital.

After arriving at the emergency room, Piper said she was beginning to understand how bad the situation actually was. She said, “A huge team of doctors and nurses were working on him and they were saying that he was going to be in the hospital for a long time.”

Piper called her husband, Tim, and told him that Jack had been “badly burned.” Tim said, “I had no idea what ‘bad’ meant at the time.”

When Piper and Tim were first able to see Jack, the reality sunk in. Piper said, “He was swollen and intubated, and the trauma had taken over his body. I knew he was fighting for his life. But I also knew that he was a fighter and would get up and walk away from this.”

The next thing Jack remembers is waking up in a hospital bed with wires and tubes attached all over his body. He said



JACK SAMPLE, SEEN HERE ON HIS WAY TO SCHOOL, SAYS HIS FAVORITE SUBJECT IS HISTORY.



THE TWO BROTHERS TAKE A BREAK FROM ENJOYING THE SURF AT SILVER STRAND BEACH IN OXNARD, CALIFORNIA.

he wasn't sure what was going on, but he did know that he was in "a lot of pain."

Jack had received third-degree burns to more than 40 percent of his body. His chest, arms, left hand, neck, and the left side of his face were the most severely injured. At one point, doctors thought that Jack may lose some of his fingers, but they were able to save them all and he has since regained full use of his left hand.

Piper said the care Jack received at UCI was "excellent" and described the doctors and nurses as "wonderful people." Jack said he didn't like being in the hospital at all, but he agreed that the doctors and nurses were "really cool."

Although Jack was receiving superior care at UCI, Piper said she was focused on "getting Jack home." Jack's fighting spirit helped him through a quick recovery, and he was released from the hospital after 6 weeks, which was sooner than the doctors had anticipated.

Making Adjustments

A huge part of Jack's physical and emotional recovery was due to the encouragement of his family and friends. He describes his mom and dad as "really cool and supportive." He also said his brother is "always there" for him.

Jack said that going back to school was "hard at first." He said that a lot of the kids stared and asked questions, but after a while people learned that he was "still the same person on the inside."

One thing that helped Jack adjust to returning to school was participating in a school reentry program.

According to Amy Clark, Family Services Coordinator for The Phoenix Society, returning to school is "a pivotal point in

a child's recovery." Going back to school, "marks a moment when a young person can reclaim his or her life and transition from burn victim to burn survivor."

School reentry programs are designed to help make the transition back to school easier. In these programs, a trained professional, sometimes a fellow burn survivor or parent, educates teachers and students about burn injuries and the challenges that a burn survivor is experiencing. The goal of the reentry program is to empower the returning student and to encourage empathy and tolerance to differences.

Jack said that sometimes people do still stare and that is hard, but he is learning how to deal with it. He has also learned how to handle people's questions. He said, "A straight answer is the best." He said he usually answers people's questions, but he has also learned to say, "I don't want to talk about it anymore," which is an important part of re-claiming power over your own life.

Another issue that the Sample family has been dealing with is the impact of Jack's injury on Clayton. Clayton witnessed the accident, and Piper said that it has been "emotionally difficult" for him. She said that he felt powerless to help his brother, which left him feeling traumatized. He has also had terrible flashbacks.

In addition, as Tim and Piper were at the hospital around the clock, Clayton had to be left with other family members during that time. Although Clayton feels badly that his brother has gone through so much, Piper said Clayton has also often felt left out.

Getting Back Into Life

Like most burn patients, Jack has had to return to the hospital for follow-up surgeries, including more skin grafts and releases, but overall, Jack has made a remarkable physical and emotional recovery. Today, he is an active and enthusiastic boy.

In addition to listening to music, Jack also plays in a band with two of his friends. They write their own music, and Jack plays guitar and piano. He describes their music as "jazzy rock," with their inspiration coming from classic groups like The Beatles and The Rolling Stones.

Jack also rides a unicycle, which he says, is "more fun and more challenging" than riding a bicycle. His favorite subject in school is history because he likes learning about people and places. Jack is also very interested in acting and directing and recently starred as Captain Hook in his school play.

Barbara Kammerer Quayle, Director of the Image Enhancement and Support Program at UCI, described Jack's

cont. on p. 17

Facial Transplants

Ethical and Practical Questions Posed

At the 38th Annual Meeting of the American Burn Association (ABA) this spring, Donald D. Patterson, MDiv, served as the moderator of an ethics case presentation on facial transplantation. His introductory remarks provided background on the first such procedure performed and posed a number of issues to be considered regarding the procedure:

On December 1, 2005, it was announced that the world's first facial transplant, albeit a partial one, had been performed in France. The response was swift and predictably varied.

The popular media accounts greatly framed the news in the image of John Travolta and Nicolas Cage in the 1997 movie, *Face-Off*, obscuring some of the substance and reality of the procedure as it was performed.

While many have hailed the operation as a major step forward in medicine, it has also brought to the fore ethical and practical questions about the procedure.

Dr. Jean-Michel Dubernard, head of transplantation surgery at Lyons University Hospital, grafted the donor nose, lips, and chin to the face of a 38-year-old woman whose lips and nose were ripped off in a dog attack several months earlier. Dr. Dubernard's credits include Europe's first pancreas transplant in 1976, the world's first hand transplantation in 1998, and the first bilateral hand and wrist transplantation in 2000. Professor Bernard Devanchelle, head of maxillofacial surgery at Amiens University Hospital, performed the surgery with Dr. Dubernard.

Following the surgery, Dr. Dubernard said at a news conference, "We are doctors. We had a patient with a very severe disfigurement that would have been extremely difficult, if not impossible, to repair with classic surgery. As doctors, if we have the possibility to improve our patient, that's what we can do."

Critics of the surgery cite several practical, psychological, and ethical questions which overlap with one another. One of those that looms large is the matter of the immunosuppressive medication that is required after face transplantation and will continue for the rest of the patient's life. The regimen carries significant medical risks, including increased risk of lymphoma and skin cancer, deleterious effects on general health, and coarsening and blemishes on the recipient's own skin. While these risks may be justified in cases of solid organ transplantation to prolong survival, the

question is raised: are they justified in a procedure that is not done to correct a terminal condition?

In the first few postoperative days, there is estimated to be a 5-10% risk of transplant failure from thrombosis of the surgical junction that pumps blood from the carotid artery through the donor's blood vessels into the transplanted skin. The immunosuppressant drugs may fail to control the immune response leading to rejection at any stage and for months or years following. Estimates of risk of rejection are 10% failure in the first year and estimates of 30-50% over the next 5-10 years. Should the transplant fail, the patient will be back to "square one" or even a negative factor from the time of injury.

"Well-meaning, well-intentioned, well-informed people can disagree, sometimes diametrically, on matters such as this."

That leads to the ethical question of informed consent. You may have noticed the repeated use of the qualifying word "estimate" in the preceding paragraph. Facial transplantation is a procedure for which there is no track record. It is highly experimental. One of the most important ethical elements in the relationship between physician and patient is informed or valid consent. Dr. Kenneth Goodman, director of the bioethics program at the University of Miami, has said, "Desperate people are poor models for the consent process. They are vulnerable by virtue of desperation." (It might be illuminating to note that the Institutional Review Board of the Cleveland Clinic was the first in the U.S. to approve the facial transplantation procedure. Dr. Maria Siemionow, who is leading the project, says that the clinic's consent form states that the surgery is so novel that doctors do not think that informed consent is even possible.) The procedure raises questions about personal identity and how people think of themselves which, in turn, raise questions about the psychological and psychiatric risks, and the answers to those questions are still very unclear.

Other significant questions include:

- Should patients be subjected to risks of transplant failure and life-threatening complications from anti-rejection drugs for an operation that is not lifesaving?

- And, in an environment of limited resources, who will pay for the procedure and the lifetime of maintenance, which could be somewhere on the order of \$250,000 per year?
- And, by what mechanism and criteria will donors be sought? Would it necessarily fall outside of the public policy and procedure that has been developed regarding the donation of solid organs?
- And, by what medical, psychological and emotional standards will recipient candidates be identified to be consistent, to maximize the potential for success, and to justly distribute resources?
- And, who will make those determinations and by what criteria? Will there be a uniform public policy similar to that which informs solid organ transplantation?

These are only a few of the top-drawer questions. There is a host of others. As with many, if not all, ethical issues, this

one has a field of gray. Well-meaning, well-intentioned, well-informed people can disagree, sometimes diametrically, on matters such as this. Almost certainly, this is a conversation that will continually and increasingly command the attention and reflection of the world community.

Donald D. Patterson, MDiv, BCC, is a member of the Chaplaincy Department at Regions Hospital in St. Paul, Minnesota. He is currently chair of the ABA Ethical Issues Committee.

The Phoenix Society and many burn survivors have been asked by the media to comment on facial transplants. To provide WBC attendees with a forum for discussion of the topic, a focus group, led by Donald Patterson and Drs. David Greenhalgh and Joe Mlakar, will be held on September 7 at the 2006 World Burn Congress.

Profile cont. from p.15

performance as “truly quite good.” In addition, Barbara said Jack is “confident and poised” and called the Samples a “stellar family.”

Jack and his family have also become active members of the burn survivor community. Jack enjoys attending the Firefighter’s Kids Burn Camp and participating in activities with the UCI burn center. Additionally, Clayton has also been able to attend burn camp with Jack.

Most recently, Jack and Piper participated in a video about school reentry, sponsored by The Phoenix Society. The video, *The Journey Back*, is designed to be a teaching tool for those interested in learning about or conducting a school reentry program. The video and supporting materials will be introduced at the 2006 World Burn Congress.

In the video, Jack provides peer support to a fellow burn survivor on her first day back at school. Jack shares how he handles public situations from a child’s perspective, while Piper talks about her experiences as the parent of a young burn survivor. Jack said he had fun making the video because he likes helping other people.

Piper also attended World Burn Congress (WBC) 2003 in Cleveland, Ohio, and called it a “wonderful experience.” She said WBC “offers an amazing gift of support.” In addition, she said participating in burn camp has been instrumental for Jack. She said, “He always comes home so positive.”

Through this ordeal, Piper said that she has learned to appreciate her family. She said, “There’s nothing that can come our way that we can’t handle together.” She is also so

grateful for the support they have received from the community. She added, “We are so loved and cared for, and I hope I am able to give that back.”

Piper describes Jack as having a “big heart and generous spirit.” She said she admires how Jack has handled this experience and that he has gained a “deeper understanding.” As for Clayton, she said she admires how he has worked through the emotional difficulty, calling him a “beautiful person.”

Searching for Answers

At a very young age, Jack learned that life isn’t fair and that bad things do happen to good people. But what matters is how you deal with it.

Today, Jack bravely says that being burned “made me a better person.”

He said, “I have a new outlook on life. I know that life is short and fragile. I try to live each day to the fullest and to treat people better.”

While most of us may still be struggling with life’s realities, Jack’s simple message can have profound impact.

No one may understand this more than Jack’s father. Tim said, “I admire Jack’s perseverance and tenacious spirit. He is able to live in the present... and I still struggle with that.”

He added, “It’s a strange thing to be an adult, and have the man you admire most be your little boy.”

Jack Sample is certainly someone we can all admire.

Nicole E. Smith is a PhD student in the School of Journalism and Mass Communication at the University of North Carolina at Chapel Hill. She is also a burn survivor.

Burn Victor Support Group

Meeting the Unique Needs of the Amish

BY ROBERT L. KLEIN, MD

Individuals subjected to burn injuries are often categorized as burn *victims* and if they “make it” are labeled as burn *survivors*. Simply living past the injury, I suppose, makes one a *survivor*. However, I think that an individual who lives and goes back into Society as a contributing member is more than a *survivor*; that person is a *victor*. Anyone who has attended World Burn Congress, listened to the open mike sessions, and heard the myriad stories from the attendees cannot help but feel that these individuals are conquerors of their injuries, physical and mental, and are more than simply *survivors*. For that reason, I use the term burn *victor*.

There is also a tendency to view all these individuals as a homogeneous group. Nothing is farther from the truth. Everyone has different needs, abilities, past histories, economic circumstances, job skills, educational achievements, mental capacity, family backgrounds and support systems, plans and hopes and dreams for the future. In other words, they are similar to those of us who have never been challenged by such an injury. Unfortunately, the in-hospital and post-hospital support systems are unable to adequately cover all the bases. In fact, patients frequently do not even have all their questions (for example, what causes scarring, how long will they last, will they change, what can be done about them, do I have to have more operations on my scars if I do not want to?) answered in a way that they can completely understand. Burn support groups such as The Phoenix Society and the SOAR (Survivors Offering Assistance in Recovery) programs attempt to address these problems. However, even with these systems in place, there are groups of people left out, often through no fault of their own.

In Akron, Ohio, the C. R. Boeckman, M.D. Regional Burn Center in the Children’s Hospital Medical Center treats both adults and children. The unit serves 17 counties in the northeastern area of the state. The population base is more than 2 million lives. Each year admissions number from 175 to 225 patients and approximately 1500 outpatients are treated, averaging about four visits per person. In an attempt to reach out to meet the various needs of the patients after hospitalization, we not only have a monthly burn survivor (victor) meeting and actively seek members, but also an annual weeklong burn camp, a long-weekend adult retreat, a Fire Stopper program, SOAR activities, an annual Christmas party,

back-to-work and return-to-school programs, and, with Aluminum Cans for Burned Children (ACBC), sponsorship of staff and former patients to attend World Burn Congress. Despite all the above programs, we are aware that there are still groups of individuals whose needs are not being met and we strive to corner these groups and see if we can be of help. Fortunately, we have learned a lesson in reaching out to an isolated population who really needed and wanted our support and are quite anxious in every way to help us help them.

Identifying the Needs of a Special Community

Nestled in the rolling hills of several counties that we serve lives the country’s largest Amish population, approximately 50,000+ people. They live simply, avoiding ownership of many of our “modern conveniences,” such as electricity and gasoline engines. They do use propane gas, gasoline, kerosene, and Coleman fuel for lighting lamps and lanterns, cooking, starting brush fires, and various other uses around their homes, farms, and businesses. Unfortunately, because of these habits, burn injuries are not uncommon among Amish people. These people are basically self-pay. After the injury is treated and the wound healed, they infrequently return for corrective operations. Because these kind souls generally travel on foot, bicycle, horse and buggy, or hire a driver at considerable expense, we were reluctant to encourage them to attend various survival meetings. The Amish community generally accepts a person based on qualities other than physical appearance and we wrongly assumed that they met their own needs in their own special way.

Troy Slaybaugh, a paramedic, firefighter, member of our ACBC program, and burn unit employee, decided significant needs among the Amish were not being met. Troy has strong connections in the Amish world and understands their religious beliefs and cultural diversities. He met with several bishops in church communities to determine if there was a need for a burn support group within the Amish community. The answer was, surprisingly to us, strongly affirmative.

Getting the Word Out

The next hurdle was how to get the word out to the community that a support group was being formed and to see

what the response was. Telephone and e-mail are not options among the Amish, who have no home phones and no computers. Roland Geiser, a former burn victim, and Troy took the names of patients and did a door-to-door canvas of three counties (no small task), flyers were posted, the Amish newspaper *The Budget* and *The Church News Letter* both printed notices, and word of mouth spread the information.

Providing the Necessary Resources

Finding someone to host the meetings was easy; many people thought that it would be an honor to share their homes for the meeting. Scheduling of meetings can be difficult as the need to plow, plant, husk corn, and make hay must be taken into consideration. In addition, travel distances for participants can be great.

Still the attendance has been generally more than 50 people, not counting the wee ones who come with their families. Topics discussed include burn care and an explanation of various treatments—fluids, dressings and skin substitutes, grafting, pain control, scarring, creams for wounds and scars, and numerous other topics. (Post-traumatic stress will be addressed in a future meeting per their request.) While these topics are covered in depth at the hospital; we have found that members of this community often ask no questions and avoid topics in that setting. However, in their own bailiwick, the questions, fears, and uncertainties pour forth. They love the sessions and request meetings at least quarterly. They have expressed how helpful and informative the meetings are and that they are not “pity

parties.” One-hour meetings may continue for 2 or 3 hours following the formal presentation to allow for additional questions, visiting, and networking among the participants. And the food brought to the meeting is out of this world Amish cooking, chicken, meats, and the pastries are second to none—just ask Barbara Quayle who has visited some of my Amish friends.

Another issue we have begun to address is the treatment of burn injuries within the Amish community. The strict Old Order Amish attempt to avoid anything remotely “modern” or “English,” their terms for anyone not Amish. In order to avoid traditional medical therapy, in many of these areas a person who is versed in Amish medical care is called upon to provide burn wound care. Troy Slabaugh has started meeting with some of these people to teach safer topical therapy and dressing modalities.

News Spreads Fast

Word of mouth and letters can spread information rapidly, not just locally, but throughout the Amish world. Proof of the success of this program is the fact that we have had requests for information from both Pennsylvania and Tennessee, including a request from Pennsylvania to attend our meetings. Of course, the answer is “absolutely yes!”

As a result of this widespread interest, discussions are underway to determine whether can find a way to meet in these communities or at least conduct a beginning seminar or initiate burn support programs, further serving the needs of the Amish burn “victors.”

Join the Fight for Fire-Safe Cigarettes

**COALITION
for FIRE-SAFE
CIGARETTES**

The time is now.™

The Phoenix Society for Burn Survivors, which has long been an advocate for fire-safe cigarettes, last year joined the newly formed Coalition for Fire-Safe Cigarettes, which is working to save lives and prevent injuries and devastation caused by cigarette-ignited fires. The Coalition is calling for cigarette manufacturers to immediately produce and market only cigarettes that adhere to an established cigarette fire safety performance standard. In addition, the Coalition is working to see that these standards for fire-safe cigarettes are required by law in every state in the country.

Fire-safe cigarette legislation has been passed in California, Illinois, New Hampshire, and Massachusetts, and has been passed and already gone into effect in New York and Vermont, as well as in Canada.

To show your support of the coalition's goals, go to www.firesafecigarettes.org and “sign” the online petition that urges tobacco companies to make the change now to sell only “fire-safe” cigarettes

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Mongeluzzi Joins Society Board

Attorney Robert J. Mongeluzzi was recently appointed to The Phoenix Society Board of Trustees. Mongeluzzi is a founder of Saltz Mongeluzzi Barrett & Bendesky, a law firm in Philadelphia that focuses on electrical injuries, construction accidents, and product liability.

Highly active in the legal community, Mongeluzzi is Founder and Chairman of the Association of Trial Lawyers of America's Electrical Accident Group and Crane and Aerial Lift Litigation Group. He currently serves on the Association's Board of Governors and was President of the Philadelphia Trial Lawyers Association in 2003-2004. He has taught other lawyers to handle electrical accident cases nationally.

After Mongeluzzi's grandfather and great grandfather were both tragically injured in the workplace, his family

discovered the devastating effects accidents can have and the value of a skilled lawyer, which influenced Mongeluzzi's decision to study law.

A 1978 graduate of the University of Pennsylvania, Mongeluzzi received his J.D. in 1981 from the Fordham University School of Law, where he was an editor of the Law Review, and an L.L.M. cum laude in Trial Advocacy in 1994 from Temple University School of Law. He is admitted to practice in New Jersey, New York, and Pennsylvania, and in the United States District Courts for the Eastern District of Pennsylvania, the District of New Jersey, and the Southern District of New York. Mr. Mongeluzzi is also admitted to practice before the United States Court of Appeals for the Third Circuit.

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Burn Survivors may call toll-free
1.800.888.BURN (2876)
Web Site: www.phoenix-society.org
E-Mail: info@phoenix-society.org

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World Burn Congress
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"Information & Inspiration"



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www.phoenix-society.org

- I need help or information. I would like The Phoenix Society to call me at _____
 - I would like to join The Phoenix Society as a:
 - Burn Survivor Member* (Burn Survivors) Suggested dues \$ 25
 - Associate Member (Families, Friends, and Firefighters) Suggested dues \$ 50
 - Professional Member (Medical and Legal Professionals) Suggested dues \$100
 - Institutional Member (Burn Centers, Burn Foundations, and Fire Dept.) Suggested dues \$150
- *Dues payment is voluntary for burn survivors who do not have the financial means to pay.*

Name _____ Address _____

City _____ State _____ ZIP _____

Home telephone number (optional) _____ E-mail address (optional) _____

- My check is enclosed. (Make your check payable to The Phoenix Society.)
 - I'd prefer to charge my membership dues to my:
 - Visa
 - MasterCard
- Card # _____ Expiration Date _____
- Signature _____ Amount \$ _____

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