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# BSTTW COMMUNITY NEWS

Volume 2 Issue 4

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## BSTTW REBUILDING LIVES

### BSTTW Auction

By: Michael Appleman, CEO

The BSTTW first year anniversary as a 501(c)(3) Non Profit

Organization, is being celebrated with our first auction. The auction will be held from October 29-November 4, 2002. We will be auctioning two new paintings that were donated by Kevin Maedgen, a burn survivor and painter. Below you will see two pictures by Kevin. Kevin is an example



of a burn survivor that works very hard to rebuild his life. In 1972, Kevin was burned in school while standing in front of a space heater, in his second grade class. Kevin's coat caught on fire. He and his friends were never taught what to do when your clothes are on fire. Kevin went to the same school that his mother taught at. His first instinct was to scream for his mother and run to her. With the help of several teachers, the fire, on Kevin's body, was put out. Kevin suffered third degree burns over 45% of his body. Most of his left hand and a part of his right hand was amputated.

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### A FAMILY AROUND THE WORLD

### Help and Hope Take Flight for Burn Survivors

By Erin Flynn, AirLifeLine Outreach Volunteer

Being a teenager, starting high school, and going through all of the usual physical changes of adolescence is difficult enough. Needing specialized medical treatment which requires traveling long distances is an extra burden about which most teenagers don't have to worry.

Sixteen-year-old Esmeralda Pineda, a burn survivor from Paso Robles, California has endured 12 years of difficult surgeries and rehabilitation. She must travel nearly 600 miles round-trip to the Shriners Hospital in Sacramento several times a year for surgeries and ongoing follow-up

care.

When Esmeralda was four she and her sister Patty in foster care, thus getting to their treatment at the Shriners Hospital or going to a fun outing can be

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and painting classes. As he rehabilitated and grew up, Kevin realized that painting was his true passion. He remembers back to his rehabilitation and is very thankful that he was able to continue his passion even though he lost parts of both his hands.

By bidding at this auction, the winner will get a beautiful picture made by a man that never gave up hope on reaching his goals and dreams. You will also be helping **BSTTW** to raise the money needed to reach the goals of rebuilding the lives of our present and future burn survivors and family members from around the world. For more information on this and future auctions go to [www.burnsurvivorsttw.org/auctionlist.html](http://www.burnsurvivorsttw.org/auctionlist.html)

If you would like to donate merchandise to **BSTTW** that can be used in our upcoming or future auctions please contact us at 941-364-8457, [auctions@burnsurvivorsttw.org](mailto:auctions@burnsurvivorsttw.org) or mail them to:

Burn Survivors Throughout The World, Inc.  
Attn: Auctions  
650 N Beneva Rd. #105  
Sarasota, Florida 34232

## **PAIN AND THE BURN PATIENT**

By: Michael N. Skaredoff, MD  
First of two parts

The skin is our interface with the outside world. Because the skin is so richly supplied with nerve endings, any serious burn is will result in severe, prolonged pain. In addition to the pain of the process itself, Most burn patients must undergo frequent dressing changes, wound cleansings and rehabilitation hydrotherapy. In addition, one must also consider myofascial pain due to immobilization, denervation pain secondary to burn injury, and sympathetically maintained pain.

Many patients at the outset are intubated, and therefore unable to make their needs known; it is

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therefore critical that the staff be unusually attentive to these issues. Usually the first step in pain control in the burn unit involves intravenous opioids (morphine, fentanyl) supplemented by benzodiazopenes (diazepam, chlordiazopoxide, lorazepam). Intramuscular administration is usually unpredictable. With less severe burns, oral intake of long acting opioids may be used, but in the INPATIENT setting, the preferred route is intravenous, controlled by the patient. Patient Controlled Analgesic (PCA) units are quite reasonable in the inpatient setting, but when the patient makes the transition to outpatient treatment, other methods need to be employed. The simplest regimen is that of a long acting opioid supplemented by smaller doses of fast acting opioid to act as a “rescue” or “breakthrough” dose. The problem with many of the short acting opioids on the market is 1) they contain a significant amount of acetaminophen, which over time may be detrimental to the liver and kidneys; and 2) most of these medications take about 20-30 minutes to work. Clearly another approach is needed. Fortunately, there is a short acting medication in an oral lozenge format (Actiq™, Cephalon) which can be efficaciously used in anticipation of a painful procedure. Severely painful procedures will still have to be done under either deep sedation or general anesthesia.

There are several special problems that impact burn patients in particular: Both adults and children may have cardiac and respiratory instability. Pain therapy must be so tailored so as to avoid these problems; in practice this may be very challenging. A second problem is hypotension that occurs as a result of vasodilation. Similar considerations apply. Nonsteroidal antiinflammatory drugs (NSAIDS) should be avoided to reduce the risk of gastrointestinal bleeding.

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Burns in Children represent another very special case. There is a tendency to deny analgesics to children. Opioids are a fine choice, but it must be borne in mind that the analgesic half-life is shorter and clearance is increased in acutely burned children. PCA therapy has been used successfully with older children; enrolling the parents in the therapeutic regimen increases the odds for success.

Look for Part 2 in the January 2003 issue.

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difficult. One reprieve for her and her sister this year was Firefighters Kids Camp, which is run by the Firefighters Pacific Burn Institute.

Fortunately, Esmeralda and Patty discovered a volunteer pilot organization called AirLifeLine. The organization's volunteer pilots will fly them to treatment at Shriners Hospital or to an exciting destination like Firefighters Kids Camp totally free of charge, for as often as necessary and as long as needed.

AirLifeLine volunteer pilot Saul Chaikin of Cupertino, California flew Esmeralda and Patty from Paso Robles to the camp in Lake Tahoe in August of 2002. It was Saul's first mission with AirLifeLine, but it certainly will not be his last. He said he enjoyed flying with the girls and enjoyed teaching the very curious Esmeralda about all the aircraft's flight instruments.

Although Esmeralda said she had fun in the air, she was more excited to get to camp. After taking a few photos with Saul, the two were met by a firefighter who escorted them to camp. Once at camp the girls were able to socialize with several other burn survivors and talk about their unique experiences or just enjoy the activities and the beautiful setting.

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"The teenagers go on outings and participate in challenges," said Esmeralda. "We have fun and just chill."

According to Monica Saldana, a representative from the Firefighters Pacific Burn Institute, the camp is staffed primarily by firefighters, along with burn care specialists and adult burn survivors. The camp is a place where children and teenagers with severe burn injuries can meet with others who have had similar experiences, but the staff makes sure it is really just a typical summer camp. The kids participate in activities such as rafting, boating, fishing and crafts.

"A lot of the kids are timid and shy when they first get there because of their scars, but by the end of the week there out there in their bathing suits." Saldana said. "They're open and not so focused on outward appearances."

Thanks to compassionate and generous volunteer pilots like Saul, Esmeralda and Patty were able to have these great experiences at camp and reach the ongoing treatment they need. Saul began flying in the early 1970's because he found it was a challenge and an exciting way to cover great distances in a short amount of time. He purchased his own plane in 1980 and has now found flying can be even more enjoyable when volunteering for AirLifeLine. Saul only recently joined AirLifeLine after reading about volunteer pilot opportunities on the organization's website. "I like to do the volunteer flying. It puts my skills and equipment to good use," he said. "It is a very positive experience." AirLifeLine is the oldest and largest national volunteer pilot organization in the United States. The organization exists because pilots like Saul want to fly for enjoyment and help others at the same time. The pilots donate, not only their skills, but also all the costs of the flight.

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AirLifeLine has been matching pilots with patients in need since 1978. Just last year, AirLifeLine volunteer pilots transported over 8,500 passengers to over 400 destinations, saving the passengers an estimated \$4 million dollars annually.

Over 40% of the organization’s flights support children, thus making sure they get the medical care they need and ensuring that they are able to experience things other children enjoy like summer camp. Without Saul and other pilots like him, Esmeralda and Patty may not have been able to enjoy Firefighters Kids Camp.

“AirLifeLine is really important and I thank them,” Esmeralda said

Through a nationwide network of over 1,400 volunteer pilots who donate their time, aircraft, fuel, and landing fees, AirLifeLine offers free air transportation for people in need. For more information, or to request a free flight, call (877) AIR LIFE or visit [www.AirLifeLine.org](http://www.AirLifeLine.org).

### **Camp Susquehanna**

By: Shirin Juwaley

Just recently I had a wonderful opportunity to be counselor at a burn camp for severely burned children. Camp Susquehanna was held at Lancaster, PA in June and is sponsored by the Sertoma Club which is a civic organization in Pennsylvania. Camp Suquehanna was organized in memory of Elvan Byler, who was burned in a plane crash, by Sertoma Club, Sertoma meaning Service to Mankind. Mr. Byler was an important member of the Sertoma Club who rendered invaluable services.

Camp Susquehanna is a wonderful opportunity for burned children to interact and learn from the experiences of other burn survivors It is an excuse

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to be free and enjoy the summer without making the effort to belong. ”

This was my first time at a camp and I was a little apprehensive if I would be a good counselor. It was my first experience with kids and I was a little nervous. It just took one introduction with the kids and then we were friends forever. Being severely burned myself it was appalling for me to see so many kids without limbs and severely scarred and disfigured bodies. It took me a while to reel from the shock but their sheer zest for life made me extremely proud of them.

Camp Susquehanna, a four-day camp, was something every kid looked forward to. It was four days of fun and frolic and good food. It was four days away to a different world, a world of burn survivors. It was a time to be with your own kind. A time to have fun, talk and listen without explaining to one another about their burns. It was a place where one need not strive hard to belong. It was a place where everybody simply understood.

You know friends; the sad part is there is always someone worse than you. There is so much to learn and be thankful for small mercies. Just the thought, how badly these kids were burned, blew me away but I was overjoyed by the sheer courage and strength they represented. I am very proud that I was a part of such a group.

The camp had many fun-filled group activities and it gave the children an opportunity to bond with other kids. The kids enjoyed treasure hunting in the woods, which built their problem solving skills, and gave them confidence in leadership and also enabled them to work in a group. The other half of the day was spent doing canoeing, kayaking, boat rides and also rides on the ski boat. It was a day well spent on water, and believe me we had to apply ample of block crème to save us from sun the extensive sunrays. The focal point for the

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kids at the camp was swimming. Kids just loved swimming and they loved the cool water caressing their traumatized bodies. Every kid in the camp just stormed at the pool and it also gave us counselors to cool off our heels.

One night, a week before 4<sup>th</sup> of July, we went to watch the fireworks. We were atop a tall parking garage impatiently waiting for the display of the fireworks. The fireworks made a startling display of lights .It was like the sky was bedazzled with millions of colorful stars. It was a very beautiful display of colors against the backdrop of the dark clear sky. It was a very beautiful night.

There was this young girl 15 years of age and she was burned 100%. Her hands and feet were badly disfigured but she had an amazing spirit. One of the days while we were in the woods the camp organizers had organized a few challenging games. One of the games was climbing a 25ft high tree trunk by a rope ladder and then walking on a cable wire from one tree to the other twice and then just free falling on another cable wire. Of course there was a safety harness involved to avoid mishaps. This young spirited girl, with disfigured limbs climbed the rope ladder (which takes a lot of physical strength and determination) and there were times when she felt like giving up her arms and legs hurt but the group urged her to go on and she did. She completed the whole task and plummeted down the cable wire with a shri! lling shout of achievement.

One thing I've learnt that no matter how badly burned you are nothing can stop you from leading a normal life. You may have a lot of barricades in your way but with a little support and determination you will always triumph. We all need to know that we are not victims but survivors.

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PHANTOM OF THE SMOKE**

By: Cynthia E. Jackson

If I shoulda, woulda done  
would I had still been the one.

If I coulda, thoughta maybe did,  
I might not have had this gig.

Flames so hot- scorching  
like a thousand valleys of lava,  
smoothing down my face  
covering like cold cream

Severing it like a surgeons  
scalpel my visage coming  
apart sliding slowly downward  
**HOTWAX!**

What an odd candle I make.  
Wicked.

Like a Phoenix I strive to rise and fly  
but the roots entangle my foot  
Hindering me, preventing me  
from moving forward.

As I wipe the acrid fog clear-  
Who do I find near?

The Phantom of the Smoke

With whispering hands  
he creates muscle bands  
touching my eyes that well up-  
my body that swells up

Is it not enough that my  
mind is likend to catacombs  
dark, devoid of everything but dust  
disturbed and designed to choke?

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ANSWER! Ye Phantom of the Smoke

Your crackling lies have done me great harm

Licking me like a tender lover.

Hot breath on my skin

penetrating deep within

I hear your laughter snapping in my ears

You are drunk and giddy on my fears

I shall not let u claim me

though you have changed me

When once I was scared of the marks I bear

Tis' a badge to me for I have the victory

No more shall u enslave me

for my Lord has healed and raised me.

And you.... are mere Phantom!

of fire and smoke

### **Safety at the Gas Pumps: Whose Responsibility Is It?**

By: Delores Lekowski

When you think about it, pumping gas is a really dangerous thing to do, and in all but two states (New Jersey and Oregon), self-service is the way most people gas up their cars (unless they want to pay a LOT more to have a station attendant do it). Most people can recite the rules for pumping gas safely -- and for those who don't, there are signs posted right at the pumps. The rules include, from an American Petroleum Institute (API) fact sheet called "Staying Safe at the Pump":

- Keep gasoline away from ignition sources like heat, sparks and flame
- Never smoke around gasoline
- Shut off the vehicle's engine when refueling

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- Store gasoline only in approved containers

The question of whether using a cell phone while refueling, or anywhere an ignitable atmosphere may exist, is the subject of some debate. Apparently the risk is remote, but there is a risk, so why take the chance at all? I don't use my cell phone at the pumps and I don't think it's wise to ignore signs that prohibit cell phone use anywhere.

Preventing the buildup of static electricity is also a factor in safe refueling. Until I did research for this article, I wasn't aware that static electricity could cause a fire at the gas pumps, especially in cool or cold and dry climate conditions. Among the tips that API and others provide to reduce static electricity are the following (note: the Petroleum Equipment Institute has a section of its website devoted to static electricity at:

<http://www.pei.org/static/index.htm>)

- Avoid getting back into your vehicle during refueling, even when using the nozzle's hold-open latch. If you can't avoid getting back into the vehicle, always first touch a metal part of the vehicle, such as the door, away from the gas tank after you exit the vehicle before touching to the nozzle.

- Place portable containers on the ground during filling, and keep the nozzle in contact with the container. Never fill a container in or on a vehicle.

- Manually control the nozzle valve throughout the filling process, and fill a portable container slowly to decrease the chance of static buildup and to minimize spilling or splattering.

Clearly, as consumers we have a big responsibility to maintain as safe an environment as possible when we gas up our vehicles. But, we have all seen our fellow refuelers do some careless, ignorant and downright stupid things in direct violation of these

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safety rules. This puts not only themselves, but also the other customers and gas station employees in danger. As a burn survivor who doesn't want to relive the horror of being burned again, I have some opinions about this.

And so we come to a big pet peeve of mine: NEVER have I seen a gas station employee intervene to stop this dangerous conduct. Could it be they aren't aware of the dangers themselves? Did their training consist only of counting a drawer and running a register? Do they feel they're not getting paid enough to give a darn about safety?

This is where the oil companies need to shoulder their share of the responsibility for safety at the pumps. Putting up signs is fine, and probably covers them in the event that they're slapped with a lawsuit, but it's not nearly enough. They need to train their employees to recognize unsafe pumping practices of their customers and give them the authority to intervene before tragedy occurs. Employees can talk to us over a loud speaker to inform us how to use the pumps, but I have never heard them tell a customer to immediately stop fueling and put out their cigarette or turn off their vehicle. People who decide the rules don't pertain to them should not be permitted to get away with putting the rest of us in danger.

How can the oil companies ensure our safety? What is the answer to stopping the dangerous carelessness of others? For starters, when the posted signs are ignored, an employee should intervene. If employees can turn on the pumps from their workstations, they can turn also them off from their workstations. When an employee sees someone committing an unsafe act while pumping gas, they should shut down their pump and tell the customer, via way of speaker, why their pump has been shut off. Once someone has had their pump shut down a few times, it wouldn't be long before they follow the posted signs.

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Just as the oil industry has a right to make a profit off of us, we have the right to insist that our safety is a foremost concern of this industry. Safety at the pumps is their responsibility, too.

**Is Your Sleep Renewing You?**

By: Debra Moore, Ph.D.

First of two parts.

Considering the fact that we spend a third of our life doing it, you'd think we'd be more informed about sleeping. Most of take it for granted until it becomes a problem. Then we're likely to either apply old wife's tale remedies or take powerful medication which can make the problem worse.

For the next several Sundays, I'm going to explore the world of sleep. What you need, how to know if you're getting it, and what to do if you're not. I'll talk about do's and don't of sleep medications and naps. I'll also have some advice for shift workers and travelers. Finally, I'll address the myths and realities of how sleep changes with age, and what to do if you or your partner suffers from the potentially life-threatening disorder of sleep apnea.

The third of your life you spend sleeping has tremendous effects on the other two thirds of your life. We tend to think of sleep as passive, but it is actually a time of intense and important activity in our body. The amount and quality of your sleep affects your mood, energy, weight, memory, thinking, creativity, immune system, and risk of having an accident!

Before the invention of electricity, people slept ten hours a night. Modern sleep lab research has recently confirmed their wisdom. Ten hours is in fact what we need for optimal benefits. Yet very few of us get this much. The average America now gets only seven hours of sleep per night, and one third of our population gets less than six hours.

While a very few of you may experience optimal

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productivity at this amount of sleep, some of you are running on fumes!

And we are all impacted by these statistics. Consider these findings: thirty percent of high school and college students fall asleep in class at least once a week, and fifty-six percent of shift workers fall asleep on the job at least once a week; thirty-one percent of drivers have fallen asleep at the wheel at least once, causing at least 100,000 auto accidents annually; and the National Transportation Safety Board has declared fatigue the number one detriment to pilot safety.

According to recent Gallup polls, 56 percent of adults report daytime drowsiness is a problem, and 49 percent suffer from insomnia. The percentages are going up steadily.

In spite of this, few doctors ask about sleep. William Dement, director of the Sleep Laboratory at Stanford University estimates that less than one percent of case histories include a sleep history. We are starting to realize the importance of good diet and proper exercise. But so far, our education about the role of sleep is lagging far behind. It's only been two years that the American Medical Association has recognized sleep disorders as a specialty.

So if you often feel sluggish, have less than optimal sleep patterns, but haven't really looked into it or educated yourself, you're not alone.

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### **BSTTW CONTACT**

### **INFORMATION**

#### **Emergency Contact**

We have an Emergency Email Form on the Internet. Go to: [www.burnsurvivorsttw.org/emergemail.html](http://www.burnsurvivorsttw.org/emergemail.html)

You, your family and friends can also reach us by phone at 941-364-8457. If we are not in the office or it is after hours, you will be given an emergency number to call. A support team member will respond to you within 24 hours. **BSTTW** has at least one individual on call 24 hours day/7 days a week to meet everyone's needs.

#### **BSTTW Directors**

Michael Appleman: **Executive Director**  
[michael@burnsurvivorsttw.org](mailto:michael@burnsurvivorsttw.org)

Nguyễn Thi Diệu Trân: **Director- Việt Nam**  
[tran@burnsurvivorsttw.org](mailto:tran@burnsurvivorsttw.org)

#### **DONATIONS**

As a 501 (c)(3) Non Profit Organization, all donations, big or small are tax deductible to the extent of the law. **BSTTW** accepts donations for our general fund, the “Dwight Lunkley Racing To Victory” fund, the Vietnamese Burned Children fund and the World Burn Congress fund. Donations from Companies, Churches, Organizations, Communities and individuals will help **BSTTW** to do the work that is needed for all Burn Survivors, family members and the public around the world. Remember your donations can be money, clothes, a used bicycle etc.. All will help burn survivors and their family. Many families loose their homes and property. Please personally think about and talk to your family and friends about donating to **BSTTW**.



Mail your donations to:

Burn Survivors Throughout The World, Inc.  
650 N Beneva Road #105  
Sarasota, Florida 34232

Donate on line at:

[www.burnsurvivorsttw.org/donations.html](http://www.burnsurvivorsttw.org/donations.html)

If you have any questions call us at 941-364-8457

or email **BSTTW** at:

[donations@burnsurvivorsttw.org](mailto:donations@burnsurvivorsttw.org)

### Volunteering your time to **BSTTW**

We always can use your help. There are many children, adults and families around the world that need support and other help. You can take part in rebuilding the lives and helping people reenter their community. If you are interested contact **BSTTW** by phone or email us at

[volunteers@burnsurvivorsttw.org](mailto:volunteers@burnsurvivorsttw.org)

### Purchases

**BSTTW** has an online store were you can purchase Skin Care Products, Books and Video Tapes. Got to: [www.burnsurvivorsttw.org/sales.html](http://www.burnsurvivorsttw.org/sales.html)

You can also purchase Skin Care Products by phone.

### **BSTTW ADDRESS & PHONE NUMBERS:**

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