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# BSTTW COMMUNITY NEWS

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## BSTTW REBUILDING LIVES

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### BSTTW Opens An Office In Texas

By: Michael Appleman, CEO

**I**N December 2006, **Burn Survivors Throughout The World, Inc. (BSTTW)** packed their bags, moved our Florida office from Sarasota to Hollywood, Florida and opened up a new office in Conroe, Texas.

After several board meetings and a great deal of discussions, the **BSTTW board of directors** agreed that it would benefit both **BSTTW** and the burn survivor communities in the USA and Mexico if **BSTTW** opened up an office in Texas and move their current Sarasota, Florida office to Hollywood, Florida.

**BSTTW** is currently registered as a non profit organization in Colorado, Florida and Texas. All donations to **BSTTW** are tax deductible on both individual and corporate tax returns to the extent allowed by the IRS. With the help of corporations, governments, organizations and the general public **BSTTW** has raised the funding, medical supplies, medications, legal advice and the volunteers needed to offer the help needed to burn survivors, family members and to increase public fire safety awareness.

**BSTTW** is looking for volunteers, financial, medical and other donations. To learn more, you can contact Michael Appleman at 936-647-2256. You can mail all of your **BSTTW** donations to:

Burn Survivors Throughout The World, Inc..  
16193 Lone Star Ranch Drive #102  
Conroe, TX 77302



If any of you reading this article are interested in becoming a **BSTTW Volunteer**, you should fill out and submit the **BSTTW Volunteer E-Form** at <http://www.burnsurvivorsttw.org/volunteer/volunteer.html>. If you are unable to go to the internet, have any questions or have trouble filling out and/or submitting the **BSTTW Volunteer E-Form** you can contact Michael Appleman, CEO at 936-647-2256.

### A FAMILY AROUND THE WORLD

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## Massage Reduces Post-Burn Pain and Itching

Burn patients reported less itching, pain and anxiety, and an improvement in mood after receiving massage, according to a research study. The study, "Post Burn Itching, Pain, and Psychological Symptoms Are Reduced With Massage Therapy," was conducted by researchers at the Touch Research Institute at the University of Miami School of Medicine and published in the *Journal of Burn Care and Rehabilitation*.

Twenty adult burn patients were recruited from a university outpatient center to participate in the study. Individuals were in the remodeling (the reconstruction or reshaping of the wound as it heals) phase of wound healing, approximately 118 days after injury. They had moderate-sized wounds and complained of severe itching. They were randomly placed in either a control group or a massage group. Both groups received standard medical care that consisted of an examination by a doctor, medication and physical therapy.

Those in the massage group received twice-weekly, 30-minute massage sessions for five weeks. Massage therapists massaged the wound area with moderate pressure, using cocoa butter as a lubricant. Cocoa butter was applied to the wound area in a stroking manner, and therapists pressed along the wound edges and stroked toward the center of the wound. Massage therapists also used circular, transverse and vertical strokes for 10 minutes on the wound. The skin was rolled in all directions and then long, gliding strokes to the entire affected area were used to end the massage.

Measurements taken included an itching and pain rating based on the McGill Pain Questionnaire; the State Trait Anxiety Inventory (STAI), which measures feelings at the present moment; and the Profile of Mood States that measures depression. Results showed that those in the massage therapy group experienced a reduction in pain and itching, a decrease in anxiety and improved mood, as compared to those in the control group. The

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measures showed long-term improvement from the beginning to the end of the study.

"Our findings are encouraging because massage therapy provides a natural and effective alternative for the reduction of itching, pain, and psychological symptoms that are commonly experienced by patients with burns after they are discharged from the hospital," the study authors wrote. "Future and long-term studies might examine enduring effects of massage therapy for scar tissue healing, including reduction of the height of the scar and improvement in vascularity, pliability, and pigmentation."

- **Source:** The Touch Research Institute. Originally published in the *Journal of Burn Care and Rehabilitation*, 2000, Vol. 21, pp. 189-93.

## CAMP HOPE

### *Youngest burn survivors help prove that massage heals*

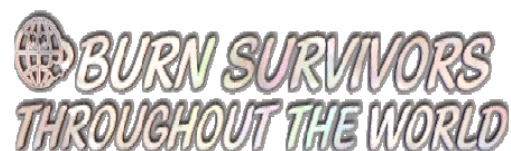
By: Clare La Plante

As Nancy Keeney Smith can tell you, life can change in a split second.

On November 18, 1986, a typically cool and sunny late-autumn day in Gainesville, Florida, Smith, then 29, was riding her bike to work. Life was good—Smith was recently married, and had a job she liked as a disk jockey at a local radio station.

Without warning, a school bus driving on the shared road made an illegal turn into the bike lane, knocking Smith over, and dragged her some 60 feet down the paved road. The bus demolished her bike, and the friction from the road tore the skin from her left leg in a severe case of burn-like "road rash."

With her husband of one-and-a-half years by her side, Smith spent the next six weeks in the **CONTINUED Page 3 "CAMP HOPE"**



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burn unit of Shands Hospital at the University of Florida where she began the first of more than 30 surgeries, mostly skin grafts. She also underwent physical therapy and debridement—an immensely painful procedure where the non-



living skin is surgically and chemically removed so that the skin underneath might have a chance to live.

Once home, Smith’s life returned to quasi-normal—she was able to stop the narcotic pain medication, she finished the physical therapy for range of motion, and she returned to work, although this time in marketing, which was less stressful than disk jockeying.

Normalcy returned with a vengeance with the birth of her children—a son in 1990 and a daughter in 1992. However, by this time, the grafted skin on her left leg had caused chronic lymphedema—swelling from accumulated lymphatic fluid. The doctors’ only recommendation was bulky compression garments and several hours of bed rest a day, a tall order for a working mother of two young children.

In frustration, Smith turned to a friend, a personal trainer who was also a student at the Florida School of Massage, for exercise suggestions. The friend, who had just taken a class in sports flushing (a drainage technique), had a better idea. She asked Smith if she would be a case study for her.

Smith hesitated at first. “With traumatic scarring, you’re very conscious of anyone outside your personal sphere seeing your

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injury,” says Smith. With doctors offering no other feasible alternative, she gave it a try.

After 20 minutes of massage, “the edema was flushed out for 24 hours and the color changed from red-purple to almost natural skin tone, a tone that I hadn’t seen in years,” Smith says. She’s had no surgery since, and was able to stop her daily dose of 2500 mg of ibuprofen.

**“What If ?”**

Over the next few years, she continued receiving massage. On September 11, 2001, when the planes hit the Twin Towers, she had an epiphany. “I realized how quickly your life can change, especially with [my accident]. I needed to do something more valuable in my life. Exactly a year later I started massage school.”

She graduated from the Florida School of Massage in 2003, with a vague notion of helping other survivors. A year-and-a-half post-graduation, while working part-time at the school as she built her practice, fate took a hand. Another burn survivor, a woman named Rose Dean, 45, a nurse from Gainesville, who had been scalded over 55 percent of her body as a 19-month-old when a vaporizer’s hot content fell on her, came to the school’s front desk while Smith was working and asked for massage therapy for her scars.

With permission from the school, Smith began an independent study project with Dean. For six weeks, in 15-minute sessions, she massaged contractures on Dean’s arm. Dean, who for more than 40 years had not been able to flatten her right hand on a surface, was now able to.

More importantly, the relationship between the two women blossomed into a game of “What

if,” hypotheses of what life would look like if massage were a part of a burn survivor’s care. “Massage is not incorporated in any [burn] aftercare,” Smith says. Doctors typically do not recommend or prescribe it. “As Nancy was massaging me, it came to me—what if I had had massage on a regular basis during my

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formative years? Would I have needed surgery when I was seven?” says Dean. (Dean had follow-up surgery when she was seven, and nearly died from an operating room infection). She firmly believed not.

Joyce Welch, an administrator at the Shands burn unit, had been trying to recruit Smith to volunteer as a counselor at Camp Amigo, a burn camp for children, sponsored by southeast Florida firefighters. Each year the camp hosts approximately 40 children, ranging from 6 to 18 years old. The camp assigns a counselor to each child—usually a firefighter or adult burn survivor.

One day, Dean and Smith had a new “what if” question: What if, instead of going as a counselor, Smith went as a massage therapist?

Smith contacted the camp’s directors and was given permission to bring her massage table to the next summer’s camp in July 2005. She also received permission from 18 of the attendees’ parents. In July, she took a week’s vacation from her job and headed off.

Smith arrived in the panhandle town of Cape San Blas in the fully accessible Billy Jo Rish State Park one day ahead of the kids, and prepped in a cabin that sat on a stretch of white sandy beach with mile-high sand dunes and sea grasses. She knew she was to work on 18 children, ages 8 to 17, who were all six months post-burn. What she didn’t know is how they’d respond.

The children were leery, she says. Many would walk into Smith’s cabin—often from a beach game or arts project—and ask, “What are you going to do to me?” Smith didn’t say much. She simply showed them her compression garments and injured leg and said, “Massage helped me. I hope it will help you, too.”

She also told the children that they could say stop at any time. “They had the whole power,” she says. By the end of the week, the kids had opened up, she says, even the youngest ones. One young girl shared how she was teased at

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school. Another said that the scars on her feet usually scared those who saw them.

After the week’s sessions, Smith drew a series of faces—from frowning to smiling. “I asked them to point to a face before and after session,” she says. “The second child on the table—an 11-year-old softball player who had burned the back of her knees on a mini-bike and had range of motion issues—said that we needed another category. ‘Happy Plus,’ she said, ‘because I feel great.’”

**Gathering Evidence**

Smith finished the week inspired. She returned to Gainesville and told Dean about her camp experiences. They took their “What if” game up a notch: What if they could prove that massage



helps these kids? As a nurse, Dean understood that the medical profession loves concrete proof. “I wondered how we could put the results in language that the doctors would understand and appreciate,” she says.

So Smith began planning the Camp Amigo Project—a study to prove that massage helps burn survivors. Diane Garrison, BA, LMT, a student at the Florida School of Massage and a burn survivor, jumped on board. She had grant writing experience and helped Smith to complete an already partially written grant, which was submitted to the Massage Therapy Foundation. The foundation awarded the Camp Amigo Project a grant of approximately \$5,000 in 2006.

Two other Florida School of Massage students, **CONTINUED Page 5 “CAMP HOPE”**

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Rachel Torres and Dana Rubin, joined the team as well. Smith then combined forces with Annie Morien, PhD, a physician assistant, licensed massage therapist and part-time instructor at the Florida School of Massage. Morien’s research interest, coincidentally, was keloid and burn scars. She helped them with the language and research protocol of the study, and with writing up the results for—they hoped—publication in a scientific journal.

Together, Morien and Smith wrote an objective: “To determine if therapeutic massage intervention produced clinically meaningful changes in range of motion and keloid size/shape in children ages 8 to 18.”

The four therapists—Morien stayed at home and would receive the results upon their return—headed to Camp Amigo in July 2006. In the medical cabin they shared with the other medical personnel, Smith and Rubin massaged eight children three to five times a week for approximately 30 minutes, while Torres and Garrison measured the range of motion, mood and circumference of scars. (The control was the same child but a different area of the body.)

They ran into a few kinks. First, they realized that scar circumference was tough to measure in camp conditions. Sun, for example, can cause keloids to pucker. Mood was difficult to measure as well. “Because the kids were at camp, they came in a happy mood and left in a happy mood,” says Morien.

However, range of motion was a slam dunk. “Range of motion was significantly increased from the first day of camp to the last day,” says Morien. In fact, she was surprised at how quickly it increased.

The non-clinical results also wowed Smith and her colleagues. “There was one little girl who had been burned in a house fire—they were using candles in the home because they didn’t have electricity—and this little girl tried to save several siblings,” says Smith. In doing so, she received burns over 85 percent of her body, including her face and hands.

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“She didn’t want to be touched,” says Smith. “She was very guarded about anyone getting into her personal space.” However, by the end of the week, Smith says, the young girl was complaining because she had to get off the massage table.

The tangible results were two-to-three degree change in range of motion each day. The intangibles were great, too. “What a wonderful turnaround! It seemed to make a difference not just in the scars, but in her heart healing, and in her body image and perception of herself.”

For Garrison, who had been the same age as many of the children at camp when she had been burned over 65 percent of her body at age 11, going to camp was a revelation. “I went to massage school to specifically help other burn survivors,” she says, but didn’t know where to find them. “Once burn survivors are through with critical [care], they just kind of disappear,” she says. “I thought, ‘This is my tribe.’ I’ve been looking for this my whole life,” she says.

Garrison was thrilled with the results. “You kind of feel that you are your deformities, your scars,” she says. “And when somebody touches you lovingly where you have horrible scars that others are repelled by, it goes beyond anything that you may be doing physically to the skin...that’s what these kids were saying.”

**Reaching More**

While Smith and Morien saw success as well, they’re ready to up the ante. “I’m excited with the results,” Morien says, “But I’m also a scientist and, therefore, cautious. I’d like a greater sample size for a more robust effect.” They hope to return next year, with more massage therapists, if possible, working on more children.

Smith wants more massage therapists on board in general. “We do not have enough trained therapists right now to handle the burn population,” she says. She says that therapists will likely find the work tremendously satisfying.

“For me, as a therapist, to be able to work with  
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burn survivors, or anyone with traumatic scarring, to acknowledge where they are in the process and introduce appropriate touch—well, I can't explain the feeling I have after a session—I'm just so *full*,” Smith says. “They realize that it's OK—that they're OK—and they start to accept themselves more.”

Garrison says that, as the kids at Camp Amigo proved, touch can be so much more than skin deep. “I've found that the psychological side is as important as the physical. You start to accept that your body may look different, but you're still lovable and worthy of touch, and that it doesn't have to hurt. For me, it's very transcendental. I heal as much as they heal.”

*Clare La Plante is a freelance writer based in Evanston, Illinois. She is a regular contributor to mtj and her work has also appeared in a number of national business publications. Clare is also the author of Wall Street on a Shoestring. (Avon Books, 1998).*

**Q&A**

**with Annie Morien, PhD, PA-C,LMT, Nancy Keeney Smith, NCTMB & Diane Garrison, BA, LMT**

### 1. When working with a burn survivor client, how should therapists approach the scars?

First, approach the person, not the scar. If you understand the person, the emotional and physical being, you will have greater understanding of the scars.

Second, go slowly. People with burns have emotional scars, in addition to physical scars. The psychological component can be entrenched for years, producing behaviors such as hiding scars, avoiding touch and inability to discuss their scars. Also, go slowly with making physical contact with your client. Touching scars may be painful.

Third, listen to your clients. They must direct the massage. Encourage them to express their feelings and goals for each session.

Fourth, be patient. Some sessions may consist of very little massage and more conversation.

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Both you and the client can explore the depth and meaning of the scar—each client is different. Again, sessions should be tailored to the individual, not the scar.

### 2. How is burn scar tissue different than regular tissue, in terms of pliability, feeling, sensation, etc.?

We've all touched non-burned tissue—typically it's soft, elastic, smooth in texture and has a nice pink color. Burn scars “feel” different—the temperature, color, texture and elasticity is different. These characteristics vary depending on the type of burn (chemical, thermal, etc.), depth of the scar (surface versus deeper loss of muscle and fat), location of scar (contracture over a joint) and age of the client (older people take longer to heal). New scars feel different from old scars.

### 3. What is the difference between working with new scars versus older scars?

In general, new scars go through a cellular maturation process for approximately 6 to 18 months, perhaps up

to two years. New scars tend to be extremely sensitive, itchy (pruritic) and have greater pigmentation (a purple or blue hue). When touching a new scar, you may feel extreme coolness or warmth. Scars can feel “stiff.” This varies depending on the thickness of the graft, depth of the scar, whether underlying fascia and muscle was destroyed, etc.

Older scars tend to be less flexible, less pigmented and less itchy, but this is variable also. The sensitivity can range from complete lack of feeling to extremely sensitive. A colleague of mine describes old scars as “feeling like a rubber tire under [her] fingers.”

The scars tend to feel thick and non-elastic, but again, this varies depending on the graft, thickness and underlying tissue.

Edema (swelling) can occur with new or old scars. The tissue feels puffy or fluid-filled under the scar, or downstream from the scar tissue. Also, new and old scars vary in dryness. Clients

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who apply moisturizers daily to their scars make our job easier. A soft lubricated scar is easier to work than a dry scar. And finally, new or old scars may change within the massage session—the texture may soften, the color changes and you feel more warmth in the scar.

**4. Which skin characteristics do massage therapists need to be most aware of ?**

I wish it were that simple. All characteristics must be monitored closely during each massage session: sensation, elasticity, pruritis, vascularity, contractures and edema.

**5. What strokes or massage techniques work especially well with scar tissue? Which ones should be avoided?**

To my knowledge, no empirical research has determined the type of massage or stroke that is most appropriate for burn scars. Published studies have used various strokes and techniques on burn patients, such as friction, light massage or others.

The type of massage stroke used is dependent upon the scar. In general, lymphatic drainage assists in areas of swelling and fluid accumulation (edema), passive range of motion and stretching helps contractures and taut tissue, and light massage increases circulation, decreases pruritis, and may alter sensation. Energy work is appropriate at any stage of wound healing, provided the client can handle it. I have heard of some massage therapists using deeper work (myofascial release); however I advise caution—only very skilled and experienced massage therapists should use this technique on burn scars.

Avoid touching open wounds or skin due to increased risk of infection. Also, be aware of your client’s level of sensation. Massage can cause pain or increased sensation in scars. There is a potential to damage the skin and produce additional skin defects if the therapist is overzealous in the treatment.

Keep in mind that the characteristics of the scar (depth, amount of tissue involved, location,

level of sensation) as well as the age of the scar indicate the type of massage that is appropriate. And sometimes, just letting the client talk about the scar is the best therapy.

**6. What are some other conditions that may produce scar tissue?**

Any time you open the skin you will produce a scar. One example is trauma to the skin. We see this on a daily basis when clients point to their childhood (or adult) injuries such as skinned knees and elbows. Also, surgical cuts produce scars. For example, mastectomies, open-heart operations and abdominal incisions produce scars.

**7. Is there a different approach to other types of (non-burn) scar tissue?**

Yes and no. Yes—each scar is unique, whether it is a surgical scar or burn scar. The therapist must tailor the session according to the client’s goals and the type of scar. No—damage to the skin is damage to the skin. The client will have some degree of altered sensation, circulation and function, regardless of the type of scar.

**8. What are the differences in approach, if any, when working with children who have scar tissue?**

Young children are extremely sensitive. While in the hospital, they learn quickly to associate a white coat or hospital scrubs with pain. Therefore, when approaching a child with healed burn scars, go slowly. Let them lead you. Approach their feet, rather than their head. Massage non-burned skin rather than scars. Get them to laugh, be relaxed. Once a child trusts you, you can start working with his or her scars.

Adults are also sensitive, but have the maturity to rationalize their feelings. However, I advise the same: go slowly, listen, be patient. Remember, adults can have years of psychological scarring.

**9. What kind of training do therapists need to work with burn survivors, or those with scar**

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tissue?



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## BSTTW COMMUNITY NEWS

### Skin Creams

By: Aliesh D. Pierce

#### **Moisturizers, Humectants and Emollients:**

One of the most commonly mis-diagnosed aspects of skin analysis is skin type. When someone has “oily” or “combination” skin there are visible characteristics; the skin seems thicker and may have a heavy sheen or enlarged follicles. Acneic skin has visible congestion in the form of papules or pustules. But dehydrated skin is often improperly labeled as being a “dry” skin type. That’s because the sweat glands and oil glands are closely connected. Water evaporates from the body to keep skin cool and oil is secreted to seal and protect.

“Full thickness third degree burns and graphed skin sites don’t have oil or sweat glands” states Debra Kayden, RN is Outreach Coordinator at UC Davis’ Regional Burn Unit in Sacramento, CA. In burn scars, the entire moisturization process is impaired or annihilated. “That’s why it’s so important to understand the difference between moisturizers and emollients.” Kayden suggests, “If you’re in a chronic state of dehydration; go for moisture. Intake enough water and limit alcohol and caffeine because they’re natural diuretics”. She tells patients, “the best process would be to apply a moisturizer and, within 15 minutes, apply an emollient on top”.

There are several products that claim to reduce scar tissue. But, regular massage and pressure therapy is more effective than the use of any specific scar cream. It really doesn’t matter what you use. “Each individual should find what their body responds to” says Kayden. Burn Survivors should treat the skin four times a day and have a thorough understanding of ingredients.

Petroleum based products are useful in blocking bacteria during the healing process. But, if used alone, over time petrolatum, mineral oil and paraffin simply trap natural oils in and block out moisture. They are also known  
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to break down the fibers in pressure garments.

Look for products containing large amounts of water and humectants to ease pruritus, itchy skin.

<u>INGREDIENTS</u>	<u>PERFORMANCE</u>
EMU OIL	An emollient; anti-inflammatory, skin penetrating
ALCOHOL (ethyl, cetyl, stearyl, cetearyl)	Used as a solvent and emulsifier. Can be very drying.
LANOLIN OIL	An emollient, humectant and sealant; wool wax; from the oil glands of sheep, contains up to 30% water.
ALMOND OIL	AN EMOLLIENT; EASILY ABSORBED, CALMING
JOJOBA OIL	AN EMOLLIENT; A BOTANICAL SUBSTITUTE FOR SPERMACE TI, NON-ALLERGENIC; CLOSE TO SKIN’S ACTUAL SEBUM
COCOA BUTTER	AN EMOLLIENT; ABSORBS QUICKLY , HIGH IN ANTI-OXIDANTS
SQUALENE	AN EMOLLIENT; DERRIVED FROM OLIVE OIL, CLOSE TO SKIN’S ACTUAL SEBUM
HYALURONIC ACID	A HUMECTANT; BINDS WITH UP TO 300 X’S IT’S WEIGHT IN WATER
SHEA BUTTER	AN EMOLLIENT; HIGH IN VITAMIN E AND A, LINOLEIC ACID AND UV PROTECTION
NEEM OIL	AN EMOLLIENT; WELL DOCUMENTED IN

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ANCIENT AYURVEDIC TEXTS AS REGENERATIVE AND RESTRUCTURING; IT IS ANTIBACTERIAL, ANTI-VIRAL, ANTI-INFLAMMATORY AND FUNGICIDAL.

GLYCERIN A HUMECTANT; DRAWS MOISTURE TO THE SERFACE OF THE SKIN

LIDOCAINE RELIEVES PAIN WHEN TOPICALLY APPLIED TO PARTIAL THICKNESS BURNS

**HERBS, VITAMINS AND ANTI-OXIDANTS:**

Many products brag about their use of herbs, vitamins and anti-oxidants. These ingredients are crucial in protecting cells from free radical damage but they can’t always penetrate the skin. They often need to be micronized to pass the stratum corneum or outer layer of the epidermis and may actually be more effective when taken orally. They can be found in several creams and salves or as ingestible teas, tinctures and capsules.

“Healing happens from the inside out, not the other way around” says Dr. Raakhi Mohan who blends Eastern and Western philosophies in her Long Beach, CA practice. “The cells on the surface of our skin are already in the last stages of their development and are ready to be sloughed off. Delivering antioxidants to this layer does nothing for the cells which are just beginning their development. By consuming antioxidants in their natural form, through food, you allow the benefits of these antioxidants to reach all of the body’s tissues.

In addition, new skin cells are able to access and utilize antioxidants throughout their  
**CONTINUED Page 10 “SKIN CREAM”**

CONTINUED From Page 9 “SKIN CREAM” development.”

<u>INGREDIENTS</u>	<u>PERFORMANCE</u>
AGNIJITH	AN ANCIENT AYURVEDIC TREATMENT MADE POPULAR BY DR. PARAMESWARAN NAIR, FOUNDER OF THE PADANJALI TREATMENT CENTER IN KERALA. HIS BALM IS SAID TO HEAL, SOOTH AND REMOVE SCARS
GOLDENSEAL& CALENDULA	IN A SALVE THEY ARE SOOTHING AND WARD OFF INFECTION
LAVENDER	PAIN RELIEVING & ANTI-INFAMMATORY
ALOE VERA	TAKEN OARALY OR TOPICALLY , IT IS SAID TO PROMOTE WOUND HEALING; IT IS A HUMECTANT; CAN DILATE CAPILLARIES AND HAS ANTIBACTERIAL, ANTIVIRAL AND ANTI - FUNGAL PROPERTIES
CHAMOMILE	CONTAINS BISABOLOL A CALMING AGENT
COMFREY	A ROOT EXTRACT; CONTAINS MUCILAGE, TANNINS AND, MOST IMPORTANTLY, ALLANTOIN, WHICH PROTECTS AND SOOTHES DAMAGED TISSUE
ECHINACCEA & ZINC	SUPPLEMENTS STRENGTHEN THE IMMUNE SYSTEM

COLLOIDAL SILVER      ANTIMICROBIAL & HEALING

VITAMIN D            SUPPLEMENTS CAN HELP PREVENT BONE LOSS

Some of these concoctions can be costly. However, armed with the right information you're sure to make the best choice for your healing and your budget. Because, after all, it's the total quality of life that matters most. Acceptance and peace can't be found in a bottle.

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 A consumer's Dictionary of Cosmetic Ingredients, Ruth Winter, M.S., Three Rivers Press 2005



## *Anniversary of a Burn Injury!*

By Delores Gempel Lekowski

Here is yet another reason for stricter regulation of the flammability of consumer products. We all know the physical devastation a burn injury causes. What isn't common knowledge is the hidden emotional devastation a burn survivor faces. The anniversary of this injury can set off an emotional roller coaster for them, filled with anxiety, depression and sadness. To these survivors, this anniversary date is a recurring reminder of when their world changed, of when they became a different person and of when the person they had once been and looked like would never be again.

The MetroHealth Medical Center's Burn Care Center in Cleveland recently asked me to be on a panel to discuss this topic. I was a child when I was burned, and though I know I was burned in July, I never knew the exact date of my injury, so my injury anniversary has never been an issue with me. So I felt if that I was going to participate on this panel, I would need to do some research.

I polled 18 burn survivors and found that half of them were negatively impacted on their injury anniversary date. The other nine did not experience this negativity but did surround themselves with friends and loved ones on this day. The amount of time since an injury was not relevant. Some who were burned years before experienced the same turmoil on their anniversary date as those who were burned just one year prior; the pain they experienced seemed to be the same. What differs is how people react to their pain. For instance, a man who was burned 2½ years ago told me that every year he and his family have a celebration of life. Another survivor who was burned 28 years ago - or, more precisely, 28 years 8 months and 7 days ago (at the time she filled out my survey) - said she is saddened every year her anniversary rolls around. She told me that having been burned on New Year's Day, her anniversary date is easy to keep track of. She has not celebrated New Year's since then, and has a difficult time when the New Year rolls around.

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All those who participated in my survey found it important and helpful to remember their survival and to never spend this day alone but to surround themselves with friends and loved ones. And to stay away from triggers that remind them of this fateful day.

I thought I knew how my injury had affected me and my family, but I am constantly learning new things about the effects of my burn on family members. Needless to say, the effects have been far-reaching.

A burn injury is a brutal injury. If there was ever an injury that should be aggressively prevented, it is a burn injury. Yet, the efforts to do just that are continually being blocked by politicians and lobbyists who feel it is more important to protect the industries that manufacture the consumer products we buy. How about protecting the physical and emotional well-being of the politicians' constituents and of the customers who buy these consumer products from the manufacturers?

Come on, politicians and lobbyists! I am personally appealing to your conscience and sense of right and wrong, your decency. If this brutal injury can be prevented and we can save one person from it, then we need to do just that. I don't understand the complacency here. For years, the foam used in our upholstered furniture has been referred to as "solid gasoline" by firefighters. It can be made more fire resistant, as you know, so why haven't you acted on this? The flammability standards for our clothing are weak and disgraceful, and the technology exists to make clothing safer. So why isn't it?

You know the industry's point of view, but maybe you don't fully understand the ramifications of a burn injury. I am here to help you understand. Anything I can do to help move fire prevention along and give you a better understanding of the lives you can save and the pain you can prevent, I will. Please contact me at [dlekowski@neo.rr.com](mailto:dlekowski@neo.rr.com).

Wouldn't it be better to replace the anniversary of yet another burn injury with the anniversary  
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**CONTINUED From Page 11 “ANNIVERSARY”**  
of flame resistant upholstered furniture and  
stricter clothing standards?

### **BSTTW POEMS**

I began writing poems during my recovery in order to not only help himself, but to offer support and positive thoughts to all burn survivors and family member who are going through a rough time. I ask you all to never give up and continue to do what I and so many others have done during and after recovery...find the support needed to work through the rough time and continue moving forward in your life.

If you would like to submit a poem or story to **BSTTW** you can do so by email at [poems@burnsurvivorsttw.org](mailto:poems@burnsurvivorsttw.org) or [stories@burnsurvivorsttw.org](mailto:stories@burnsurvivorsttw.org). **BSTTW** also has a program on our internet site that allows you to submit your stories and poems electronically. You can submit the full story at [www.burnsurvivorsttw.org/stories/storymaker.html](http://www.burnsurvivorsttw.org/stories/storymaker.html) and your full poem at [www.burnsurvivorsttw.org/poems/poemmaker.html](http://www.burnsurvivorsttw.org/poems/poemmaker.html)

*Michael Appleman, CEO*

### **Climbing High**

By: Michael Appleman

Life has its ups and downs  
Never giving up allows us to go around

Family support is a must  
This way we may not bust

Moving forward is the key  
Never giving up is the way to be

Reaching and setting a goal  
Is the way to continue a positive roll

A burn injury is a traumatic event  
Recovery shows our life is not spent

A way to reach the sky  
Is to continue to keep climbing high

*Michael Appleman*

## BSTTW CONTACT INFORMATION

### EMERGENCY CONTACTS

**BSTTW** has a support team that is on call 24 hours a day 7 days a week to help a burn survivor, family member or firefighter deal with a burn injury and fire related emergency. You can contact **BSTTW** on the internet or by telephone. On the internet go to the **BSTTW Emergency Email E-Form** at [www.burnsurvivorsttw.org/eforms/emergemail.html](http://www.burnsurvivorsttw.org/eforms/emergemail.html) or the **BSTTW Support Team E-Form** at [www.burnsurvivorsttw.org/eforms/supportemail.html](http://www.burnsurvivorsttw.org/eforms/supportemail.html)

To contact **BSTTW** by telephone by dialing 936-647-2256 or toll free at 866-712-6164. If we are not in the office or it is after hours, you can leave us an emergency message in our voice box 44 and a support team member will respond to you within 24 hours.

#### **BSTTW Directors**

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

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

Ariel Gonzalez: **Director- Mexico**  
[ariel@burnsurvivorsttw.org](mailto:ariel@burnsurvivorsttw.org)

#### **DONATIONS**

As a 501 (c)(3) Non Profit Organization, **BSTTW** depends on donations from corporations, organizations, families and individuals. All donations, big or small are tax deductible to the extent allowed by the United States government tax laws. **BSTTW** has several different funds that you can donate to. The **BSTTW** general fund, the **Bishop Peter Nguyen Van Nho World Wide Burned Children's Fund**, the **"Dwight Lunkley Racing To Victory" fund**, **USA & Asian Burn Camp funds**, **BSTTW Healing Weekend Fund**, and the **World Burn Congress Fund**.

## **BSTTW COMMUNITY NEWS**

Your donations will help **BSTTW** to do what is needed to help a burn survivor, family members rebuild their lives. It will also be used for public awareness on fire safety and how the community can help a burn survivor reenter their community.

**BSTTW** also offers people that donate \$25.00 or higher to a free copy of the **BSTTW Music CD**. To learn more about this you should go to [www.burnsurvivorsttw.org/donations/donatecd.html](http://www.burnsurvivorsttw.org/donations/donatecd.html) or [www.burnsurvivorsttw.org/donations/donations.html](http://www.burnsurvivorsttw.org/donations/donations.html)

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**.

#### **MAKE DONATIONS PAYABLE TO & MAIL TO:**

Burn Survivors Throughout The World, Inc.  
16193 Lone Star Ranch Drive #102  
Conroe, Texas 77302

#### **DONATE ON LINE**

To learn more about donating on line go to: [www.burnsurvivorsttw.org/donations/donations.html](http://www.burnsurvivorsttw.org/donations/donations.html)

If you have any questions call us at 936-647-2256, toll free at 866-712-6164 or by email at: [donations@burnsurvivorsttw.org](mailto:donations@burnsurvivorsttw.org)

#### **VOLUNTEERING YOUR TIME**

There are many children, adults and families around the world that need support and other help. You do not have to be a burn survivor or family member to become a **BSTTW Volunteer**. All you need to do is become a **BSTTW** member and then apply to become a **BSTTW Volunteer**. If you are a burn survivor or family member, in order to become a **BSTTW Member**, fill out the **BSTTW Membership & Profile Registration E-Form** at: [www.burnsurvivorsttw.org/membership/memform.html](http://www.burnsurvivorsttw.org/membership/memform.html),

Next fill out the **BSTTW Volunteer E-Form** at: [www.burnsurvivorsttw.org/volunteer/volunteer.html](http://www.burnsurvivorsttw.org/volunteer/volunteer.html)

If you are not a burn survivor or family member you can skip the **BSTTW Membership & Profile Registration E-Form** and go directly to the **BSTTW Volunteer E-Form**.

By volunteering with **BSTTW**, you will be taking part in rebuilding lives and helping burn survivors reenter their community.

If you have any questions, you should first review the **BSTTW Volunteer E-Form**, after that if your questions have not been answered, you can contact **BSTTW** by email at [volunteers@burnsurvivorsttw.org](mailto:volunteers@burnsurvivorsttw.org), and by telephone at 936-647-2256 or toll free at 866-712-6164.

### **PURCHASES**

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

**BSTTW** also offers a free copy of the **BSTTW Music CD** to people who donate \$25.00 or higher to **BSTTW**. To learn more about this you should go to

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

or

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

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

Burn Survivors Throughout The World, Inc.  
16193 Lone Star Ranch Drive #102  
Conroe, Texas 77302  
(936) 647-2256  
Toll Free: 866-712-6164  
Fax: (936) 647-2257

Feel free to contact **BSTTW** if you have any questions and/or comments by using the **BSTTW Comment & Question E-Form** at:  
[www.burnsurvivorsttw.org/eforms/emailform.html](http://www.burnsurvivorsttw.org/eforms/emailform.html)