
BSTTW COMMUNITY NEWS

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BSTTW REBUILDING LIVES

Burn Survivor Help Denied By Vietnamese Government

By: Michael Appleman, CEO

October 30, 2002 was a very shocking day for the people in Ho Chi Minh City, Việt Nam. A very busy six story building caught on fire. Inside that building, at the start of the fire, there were several businesses. There was also an American insurance company conference and a wedding, with over five hundred people. Due to the extent of the fire and the equipment the firefighters did not have, the fire lasted 5 hours, over one hundred people were killed and over one hundred were injured.

It took the Vietnamese firefighters 3 hours just to get the hose inside the building. The Vietnamese firefighters fought the blaze for over 5 hours. During that time, the firefighters used several ladder trucks to help as many people as possible escape from the roof. Flames were raging from many windows. The firefighters were unable to reach at least one man who cried for help from a window because the firefighters lacked the proper equipment.

Smoke lingered in much of the building and over the congested district that evening. The building remained too hot to enter. Firefighters sprayed water onto the

blistering remains, hoping temperatures would cool enough for them to enter the building.



A FAMILY AROUND THE WORLD

Reports of the fire were seen on televisions in Việt Nam and around the world. So many people realized that it is possible that so many people were injured and died due to the fact that the Vietnamese Government does not supply their firefighters with the quality of equipment that the American firefighters and others have.

Shortly after the fire, both, Nguyễn Thi Diêu Trân, Vice President & Director – Việt Nam and Michael Appleman, CEO & Executive Director, contacted PACCOM in Ha Noi, Việt Nam. They requested the documentation needed, from the Vietnamese Government, in order

for **BSTTW** to gather the funding, medical supplies and medications needed to help rebuild the lives of the new burn survivors. PACCOM never responded to the request. The Vietnamese for

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 responded to the request. The Vietnamese Government is delaying the help **BSTTW** can attempt to give to their people. **BSTTW** is also willing to try to get donations needed to help the firefighters get new fire fighting equipment.

It is very sad to see so many people in need and a government hesitating to allow an international 501 (c)(3) Non Profit organization from giving their burn unit what is needed.

The American International Assurance Association was the American company, conducting a training program in that building at the time of the fire. At least six staff members died and thirty were injured in the blaze.

It is still believed that an electrical short circuit was the cause of the blaze.

Americans with Disabilities Act and Burn Survivors

By: Larry Buckfire

In 1990, Congress enacted the Americans with Disabilities Act (ADA) to short-circuit disability discrimination in the workplace. The Americans with Disabilities Act gives civil rights protections to individuals with disabilities similar to those provided to individuals on the basis of race, color, sex, national origin, age, and religion. It guarantees equal opportunity for individuals with disabilities in public accommodations, employment, transportation, State and local government services, and telecommunications. The Act further requires employers to make reasonable accommodations that will permit disabled employees to continue to work.

For those who fit within its protected categories, the ADA forbids disability-based discrimination either in the hiring process or in the terms and conditions of existing employment. For burn survivors,

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disability discrimination can be a sorry fact of life in today's employment world. The ADA can be used by burn survivors to overcome this unequal treatment in the workplace.

The biggest hurdle for burn survivors seeking to rely on the protection of the ADA is to fit within the statute's increasingly narrow definition of disability. Many of the lawsuits that are brought under the Act and there are a lot of them focus on just what it means to be disabled. While most burn victims can easily satisfy the ADA requirement that a “physical or mental impairment” exists, it may be more difficult to meet the requirement that the impairment “limits one or more of the major life activities.” A burn injury, though limiting, may not rise to the level of impairment that courts have determined to be disabling under the ADA. As a result, burn survivors should be aware of the Act's parallel protection for "perceived" disability.

When Congress enacted the ADA ten years ago, it used burn injury as an example of the kind of injury that often prompts an inaccurate perception of disability in employers. For burn survivors who suffer the stares and marginalization of co-workers and employers, this comes as little surprise. Fortunately, Congress had the foresight to realize that perception often equals reality in the workplace. For burn survivors, it is helpful to be aware of the distinction between these two concepts.

The ADA defines "major life activities" to include "those that the average person in the general population can perform with little or no difficulty such as caring for oneself, performing manual tasks, walking, seeing, hearing and working." To be disabled in the major life activity of "working," an employee must be unable to perform in a broad range and class of jobs, not just the job he or she performed before the injury. For an injury to be

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"substantially limiting" under the ADA, it must be both lasting and severe.

Under the "perception" track of the ADA, an employee need not prove that he or she has a substantially limiting impairment. Instead, the employee must show that the employer regarded the employee as having such an impairment and that it engaged in discrimination based on its perception of disability.

For those who are disabled within the meaning of the ADA either actually disabled or perceived to be disabled the Act forbids an employer from taking any adverse job action based on disability. An adverse action includes not only termination, but demotion, pay cuts, unwanted transfers, failures to hire or any other action that adversely impacts an employee's ability to work. Both for new hires and for existing employees, the ADA requires that disabled employees be "otherwise qualified" to perform in their jobs before they can invoke the protection of the Act. A "qualified" person is one "who, with or without reasonable accommodation, can perform the essential functions of the employment position that such individual holds or desires."

For example, if a burn survivor is simply physically unable to perform in his or her pre-injury job, the employer is not required to make an accommodation. Also, if a burn survivor held a pre-injury job as an outdoor construction worker and his burn injury required that he work in a temperature controlled environment, the employer would not be required to accommodate him in that job. If, however, there was an opening as a data input clerk in the employer's office, and the employee had the computer skills to perform in that job, a transfer could be considered a reasonable accommodation.

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The employer is required to act reasonably with respect to the employee. Before an employee can go to court to enforce the statute, he or she must first file a discrimination claim with the Equal Employment Opportunity Commission ("EEOC"). Importantly, this claim must be filed within 300 days of the act of discrimination (i.e. termination, demotion) in order to preserve the right to bring a lawsuit. If a claim is not filed with the EEOC within this timeframe, the disabled employee will not be able to sue under the Act. In addition to the ADA, virtually every state in the country has a law that prohibits disability discrimination. Usually the state discrimination statutes parallel the ADA with one important exception.

Although the ADA is federal law and must be followed throughout the United States, each state has separate laws and remedies that may be available to burn survivors. It is important for a burn survivor facing discrimination in the workplace to contact the EEOC immediately and a private attorney to enforce his or her legal rights.

PAIN AND THE BURN PATIENT

By: Michael N. Skaredoff, MD

Second Part

CHOOSING A PAIN MANAGEMENT CLINIC

Without a doubt, there is a serious pain crisis in this country. Access to adequate (not even "good") pain management is a difficult process, fraught with a number of pitfalls and false pathways, regardless of where the patient lives. Even those individuals who have gone and researched their problem and have all the right information and are willing to stand up for themselves find it hard to find help. This is a simple step-by-step guide to finding that care.

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The obvious place to start is at the door of the primary care provider PCP. Depending on the condition, pain may be treated right then and there. Alternatively, the PCP can recommend or refer a given patient to a pain care specialist.

Alternatively, the local hospital can be called to see if any pain services are available.

In an ideal world, this would happen almost all the time; however, for a variety of reasons, many PCPs are reluctant to get involved with pain management. Pain management can be very time consuming and labor intensive, and often uses scheduled drugs which might trigger state or federal regulatory scrutiny. [That indeed is a reality that all pain clinics must deal with: extensive use of Schedule III (drugs such as hydrocodone/APAP) and Schedule II (drugs such as morphine) trigger audits--the only way to survive one intact is to have absolutely meticulous record keeping].

The upshot of all this is that a person suffering from pain has to do his/her own homework. With computer access available at many public libraries, there are several websites that can be very helpful in finding a pain clinic in your area:

1) WWW.pain.com

the Dannemiller foundation--an excellent database sorted by state and Canadian province, as well as a number of pain clinics in Europe and Australia/New Zealand

2) WWW.aapainmanage.org [209-533-9744]

American Academy of Pain Management

3) WWW.painmed.org [847-375-4731]

American Academy of Pain Medicine

The membership directory can be downloaded

4) WWW.abpm.org[847-375-4726]

American Board of Pain Medicine

5) www.asappain.com

American Society for action on Pain

Skip Baker is an activist for this group and has a database available with comments recommended

6, WWW.goedhart.com

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www.chronicpain.net

James Goedhart is another pain activist out west who runs a pain bulletin board and message center. highly recommended

What to look for:

There are, in my mind, four different types of pain management centers

1) The "block shop" this is the most prevalent -- usually this consists of a member of two of the anesthesia department of a given hospital who has an interest in pain management, and gets referrals from various surgeons(usually orthopedists) to do (primarily) epidural steroid injections or sympathetic blocks. While some patients might benefit from these procedures, many patients require more than these procedures and will need care indefinitely. The nature of any given procedure is that it is episodic.

2) Practitioners employed by or under contract with insurance companies. These practitioners are often encountered in workmen's compensation cases. Their job is to evaluate the patient and to recommend a plan of action. Because of their employment, the possibility that the desires of the insurer may color the decision making process must be taken into account.

3) The "gimmick shop". There are a number of small store-front or even much larger outfits that tout one or at most two therapies to the exclusion of almost everything else. Little used therapies (such as prolotherapy--which indeed has its place in the grand scheme of things) may be extensively used. Often, these treatments are expensive, not covered by insurance, and have to be paid for out of pocket.

4)The multidisciplinary pain clinic. This can be a single practitioner who "farms out" ancillary services or a clinic with several services literally under one roof. This type of pain clinic uses a

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variety of services, including: medical therapy, interventions (blocks) when indicated, physical therapy, counseling, and other types of alternative therapies (such as acupuncture or chiropractic) when indicated. I feel that this is the clinic that to which one should go .

You want a specialist or clinic that will do a comprehensive review of your pain problem. It really is imperative that you get all your medical records you can get. Most pain patients have long histories, and it helps a great deal to have things organized, especially:

- 1) Medications taken (dose, frequency, whether it worked or not)
- 2) Surgical procedures
- 3) Allergies and adverse reactions to medications

What you need to do before your first meeting:

Ask:

whether the practitioner is board certified in his/her speciality

what hospital affiliations

experience in treating the particular type of pain problem you have

Jim Goedhart also advocates that "THE QUESTION" be asked: "Do you use medical therapy in your pain and if so, are opioids (when indicated), part of the plan of treatment?"

This last question has to be asked with some care as it is also well known that pain clinics are also vulnerable to people having not pain but drug seeking behavior.

When you get there:

Most comprehensive first visits take anywhere from an hour to 2 hours. The visit should include:

A comprehensive patient interview

An appropriately thorough physical examination (depending on the problem)

A discussion of findings

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A discussion of the proposed plan of treatment.

Sometimes, there is so much that a given patient is overwhelmed and not much in the way of questions is asked. The solution for this is to have a companion who does not have a pain problem to be the observer and 'advocate'.

Finally, chronic pain is just that: chronic. The pain will not go away. The goal of treatment often is to increase FUNCTION by reducing pain. Research has indicated that a 50-60% reduction in pain may be a realistic goal.

The Stars of Life and the World Burn Congress 2002

By Delores Gempel Lekowski

Every big event has its own procession of stars, the shining lights of their affiliations. The World Burn Congress certainly wasn't the exception. There were so many stars in attendance that they could, and did, light up a room! These stars were "The Stars of Life," and there were 540 of them at World Burn Congress (WBC) in Phoenix this past October.

Were these stars famous people? No. Did they walk down a red carpet? No. Well, then, who and what are the "Stars of Life"? "Stars of Life" are burn survivors. Why do I call them that? The dictionary defines a star as a point of light that influences human fate, a grade of quality, outstanding, leading, a distant sun. I believe that sums up the burn survivors who were present at the World Burn Congress. Let me elaborate on why I have referenced burn survivors as part of the solar system.

To start, survivors have, in one way or another, influenced human fate. The very word "survivor" tells us this. I was greatly influenced by the journeys of the other survivors as, one by one, they stood up

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and tearfully shared their personal stories of survival and success. Each story more powerful than the last, every story filled with pride, success and bold courage. A lot of pain and tears were shared in this room, but not an ounce of self-pity could be found anywhere -- only points of light that would help brighten the way for the rest of us. Some, who thought the sunlight of their future had been dimmed, discovered through the warmth and success of others that it still can, and will, shine brightly. All of the outstanding character that was projected in this room could light up the solar system. All of the qualities society looks up to defiantly abounded at the Word Burn Congress.

I became a survivor at the age of ten and, with the exception of the last eight years, I never knew another survivor. With only my experience to relate to, I became far removed from the initial injury and the fight and courage it took to conquer this injury. As a veteran survivor, the WBC was for me a painful reminder of the past. But, at the same time, I was filled with a sense of amazement and pride for who burn survivors are and what they represent. We can all rest assured that we are well represented daily by our peers.

I am sure everyone returned home from the WBC with a wealth of rejuvenated feelings of hope and determination and each one of us left with our lives made a little brighter by the shining "Stars of Life" that made up the WBC.

Searching Our Lives

By: Michael Appleman

Life changes can be a shock
Fire can mess up and block.

After the flames and heat our life is turned
around,
How long before we get off the ground?

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Fighting the confusion can cause more pain,
Outsides can think we have become insane.

Reaching out for help can be hard to do,
BSTTW will always welcome all of you.

Our family can also feel the pain,
Externally their burn scars will never remain.

Supporting each other in so many ways,
Will help us all to pass the rough days.

Volunteering with BSTTW in the best way you
can,
Will help BSTTW & the Burn Survivor Community
to reach the goals in our plan.

Sleep Loss Has Serious Consequences

By: Debra Moore, Ph.D.

In a previous column, I reported that sleep researchers tell us ten hours of sleep is required for optimal performance. Few of us get that amount, and many of us are chronically sleep deprived. Are you among those in sleep debt?

You could go to a sleep lab to find out. You would be hooked up to a machine that tells researchers whether you are awake or asleep by recording brain waves, muscle tone, respiration and eye movement. Beginning at 8 a.m., for a 20 minute period you are put in a quiet, dark, cool bedroom and challenged to go to sleep as quickly as you can. If you do, you are awakened immediately. This test is repeated every two hours throughout the day until the evening.

If you stay awake for all the tests, you're rated fully alert. Children (not teens) usually get enough sleep and rarely fall asleep. But high school, college students, and people with sleep disorders often fall asleep within minutes. Seniors are often at least
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moderately sleep deprived and will fall asleep after five to fifteen minutes in one or more of the twenty-minute test periods, especially in the afternoon hours.

But you don't have to go to a sleep lab to know if you are sleep deprived. Try reading these descriptions. If three or more describe you, you may need more sleep.

- * I need an alarm clock to wake up at an appropriate time.
- * I often need a nap to get through my day.
- * I often sleep extra hours on weekend mornings.
- * I often fall asleep while relaxing after dinner.
- * I often feel drowsy while driving.
- * I often fall asleep within five minutes of getting in bed.
- * I often fall asleep after heavy meals or after a low amount of alcohol.
- * I often fall asleep watching TV.
- * I often fall asleep in boring meetings or in warm rooms.
- * I have dark circles under my eyes.
- * I feel slow in my thinking, problem solving, or creativity.
- * I have trouble remembering.
- * I feel tired, irritable, and stressed out during the week.
- * I struggle to get out of bed in the morning.
- * I nod off for brief periods of sleep, lasting only a few seconds at a time.
- * I'm often too tired to want to socialize or attend functions.
- * I often consume beverages or foods high in sugar or caffeine for a boost.
- * I often feel chilled when I stay up late.
- * I seem to catch every cold and flu that comes around.

Sometimes we think we're fully rested when we really aren't. If we are preoccupied with something

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stimulating, we may not notice our sleepiness. Then when we are drowsy, we blame it on boredom. But boredom alone doesn't produce sleepiness, it just produces boredom!

BSTTW CONTACT INFORMATION

Emergency Contact

We have an Emergency Email Form on the Internet. Go to: 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**
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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, USA & Asian Burn Camp funds, Burned Children fund, Vietnamese Burned Children Fund, BSTTW Healing Weekend Fund and the World Burn Congress 2003 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.

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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

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

or email **BSTTW** at:

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

Purchases

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

You can also purchase Skin Care Products by phone.

BSTTW ADDRESS & PHONE NUMBERS:

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Feel free to email us if you have any questions and/or comments at: info@burnsurvivorsttw.org