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# BSTTW COMMUNITY NEWS

Volume 5 Issue 2

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## BSTTW REBUILDING LIVES

### Rebuilding Lives: Does The Public Understand?

By: Michael Appleman, CEO

Depending on the severity of the burn injury and the individual who suffered the injury, the recovery process can take anywhere from six months to two years. Your skin has the greatest number of nerve endings of any organ on our body. This can cause an extensive burn injury to be extremely painful.

#### Hospital Visits:

Many burn victims suffer serious burn injuries that cover a large percentage of their body surface. This type of burn injury usually causes the individual to be taken to a hospital that has a specialized burn unit. Many times the family and friends are not able to visit their loved one inside the burn unit. A loved one can still offer love, friendship and support from a distance. One of the most important things you can do is make contact in some way or form in order to let your loved one know that you are there. In order to do that you should speak with the burn unit team and find out what your options are at the current time. If you cannot go into the room to visit your loved one, you can send a card, find out if you can talk by telephone or make a recording. Let him/her know that you are not only thinking about him/her but you are doing what is needed at home and everyone not only loves

and misses him/her, but is waiting for him/her to be released and return home.

When a burn patient is in a coma, suffering from severe infections, emotional distress and pain, being prepared for surgery, in the process of having wound care or rehabilitation or heavily medicated, the doctor may limit or not allow visits. Many times only family members are the only ones able to visit and their time may be limited. There have been times when a doctor increases visits from certain people who can offer the burn patient the positive energy and positive emotions needed to continue the long and hard fight to recovery.

During the recovery process, family and friends need to work together. You might want to volunteer your time and help bring something needed by the burn patient to the hospital, take the children to school, run a few

errands for the family or bring a meal or two to the hospital for family members.

#### Emotions:

Both the burn survivor and the family members go through emotional trauma. Many suffer from **CONTINUED Page 2 "REBUILDING LIVES"**



### A FAMILY AROUND THE WORLD

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depression, stress, anxiety and post traumatic stress disorder. It is very hard for others to understand not only the feelings that a burn survivor and family member suffers from, but also how they should respond.

It has been found that a many burn survivors are not comfortable discussing anything relating to their burn injury. It may remain that way for weeks, months and possibly years. It's a good idea to let the burn survivor or family member begin the conversation about the accident, hospital stay and recovery. If they begin to talk about the burn injury, you should offer love, support and be a good listener. If they do not want to talk about it, you should not pry. Wait until your loved one is prepared to open up.

Remember that each day you can go home to the usual way of life, knowing that their loved one is in a burn unit, rehabilitation center or nursing home, fighting for their life. The burn patient is left in the hospital working through the pain and emotions that remain.

#### Sympathy vs. Compassion:

If you are talking the burn patient and say "I know how you feel", do not be surprised if he/she responds in an angry way. The burn patient/burn survivor may tell you that you do not understand. You may be told that you are not suffering the pain and emotional agony that he/she is suffering. He/She may not understand that emotionally you are also in pain. You must try to understand that your loved one may have a clouded view at the time. This may cause him/her to not understand the emotional pain you are suffering.

You might what to say "I can see that this is a really difficult time. I love you and will be here for you." This may help the loved one to understand that you love and care for him/her.

If you are sympathetic to the burn survivor, he/she may take this as if you are looking at him/her funny or you feel sorry for him/her. You may not even be thinking that. As a family member or friend, you will need to continually remind yourself that your loved one is suffering

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from an unexpected traumatic injury and that he/she will work through this anger and pain in time.

You should also watch your nonverbal cues. Most burn victims/burn survivors are self-conscious of their appearance. You will need to be aware of the messages that you may be sending with your body language. This can cause a negative reaction by the burn patient/burn survivor. Try not to look shocked or afraid. Do not be afraid to make eye contact with them. But remember that staring and averting the eyes can be upsetting to patients.

#### Coming Home:

Many people assume that when a burn survivor is released from the hospital and returns home, the worst part of the recovery is over and soon life will return to "normal." That is not usually the case. Most burn survivors have said that the hardest time for them is when they first go home from the hospital. This is due to the fact that the burn survivor usually does not have as much help and support as they did during their stay in the hospital. The family will have to speak with the burn unit staff about the work that needs to be done. They may want to also speak to the doctor about having a caregiver come to the home.

#### Recovery Process:

During the recovery process both the burn survivor and family member can suffer from emotional difficulties. They must deal with the fact that their lives have changed forever. The burn survivor goes through both emotional and physical changes. He/She must find the energy to do what use to be extremely easy. Many things that were in their normal routine cannot be done. Family members must work through their emotions and learn how to their loved one.

#### Family Friends Part of The Recovery Process:

Most burn survivors say that a strong support system of family and friends is one of the most important factors in their successful recovery from the burn injury. The family members and need to find a new direction in life and the **CONTINUED Page 3 "REBUILDING LIVES"**

**CONTINUED From Page 2 “REBUILDING LIVES”** support needed to work through the emotional issues and public difficulties.

When an adult, child or teenage burn survivor leaves the hospital, after suffering through the physical and emotional trauma relating to the burn injury, the burn survivor now has to deal with coming home and facing the areas of his/her usual life that he/she is unable to take part in. Many need to deal with going back to school, work, finding different responsibilities at home or filing for disability. Others must continue the recovery stage both physically and emotionally.

The family members need to learn how to adjustments needed and at the same time work through their personal emotions and deal with the loved ones feelings of pain and anger.

The burn survivor needs to rebuild their self-esteem and feelings of being different. Many are angry at God for allowing this to happen to them. Others are angry at the individual(s) that caused them to suffer the burn injury. Some do not understand why they survived while other individuals died.

It is very important for burn survivors to meet and get support from other individuals who have experienced the same type of injury, pain, rehabilitation and social consequences.

All of us must remember that for each burned patient, burn victim and burn survivor, there is at least one family member who has suffered emotionally. The emotional trauma from a traumatic event is not limited to the person bearing the external. It extends to the immediate family and beyond. Family members struggle with feelings of guilt and sadness as they contemplate their loved one's future. Some families must also resolve the loss of family members.

The neighborhood should take part in helping both the burn survivor and family members recover. The burn survivor will need support and positive feedback when reentering the community. **BSTTW** can help educate the

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community on the stages of recovery and how they can take part in the recovery process.

Support groups for burn survivors and family members, email groups, weekly chats, weekend get togethers are important parts of their recovery. The World Burn Congress (WBC) is another important part of a burn survivors and family members' recovery. At the WBC the burn survivor community comes together to share a few days of enjoyment, friendship, emotional support and education. During the few days at the WBC a burn survivor can release his/her fears, be look at like an individual and just feel at home with people who not only understand but truly care for them.

### Being A Burn Survivor Mentor:

If you are a burn survivor you understand that from the moment you suffered the burn injury your life changed forever. You suffered a tremendous loss. That loss was physically, emotionally and financially. Many burn survivors have said that the initial trauma and painful medical suffering that was endured during the first few, days, months and for some years, was no match for the life-long emotional struggle they have been going through.

**BSTTW** has a support team of burn survivors, family members, and counselors who donate their time to offer advocacy, education, friendship and referrals to help both the burn survivor and family member. The **BSTTW Support Team (BST)** offers the following:

1. Hospital Visits
2. Face To Face Home Visits
3. Telephone Calls, Including a toll free 800 number
4. Private and Group Internet Chats
5. Emails
6. Medical Referrals
7. Medical Supplies
8. Fund Raising

You can contact the **BSTTW** at [www.burnsurvivorsttw.org/eforms/supportemail.html](http://www.burnsurvivorsttw.org/eforms/supportemail.html)

## The Burn Community's Can-Do Spirit

By Delores Gempel Lekowski

Our fast-paced society seems to get quicker every day, but that doesn't stop us from taking time from our busy schedules to join together and help our fellow humans both here in the United States and in foreign countries. This happens all the time in the burn survivor community. A recent example of genuine kindness in our community is helping create a burn unit for residents of the Mexican state of Coahuila, which borders Texas.

Due to the burn community's can-do spirit, this Mexican state will soon have a Ferno Whirlpool Tank to start its first burn unit. Ferno Performance Pools ([www.fernoperformancepools.com](http://www.fernoperformancepools.com)), located in Wilmington, Ohio, is a leading supplier of therapy and rehab equipment.

When a burn does occur, time is of the essence. Currently, Coahuila residents are at a disadvantage, because the nearest burn facilities are located across the border in Texas. Ferno's tank will provide much-needed hydrotherapy for Coahuila burn victims. Hydrotherapy is a proven method to limit the severity of a burn injury, while providing the patient with a sense of mobilization and comfort.

### Burn Survivors Throughout the World Inc. (BSTTW)

(<http://www.burnsurvivorsttw.org/home.html>) is donating the used tank to the Mexican region, thanks to the generosity of Harry Sarnoff and a grant from Ferno Performance Pools to help with storage and transport of the equipment. Assistance from others in the burn community has been crucial in choosing the appropriate grantee and ensuring delivery of the equipment to the Mexican government.

Michael Appleman, who has been a burn survivor since 1998, founded **BSTTW** in 2001 to help burn survivors and their families around the world "find their new path in life." Ariel Gonzalez, director of **BSTTW's** Mexican division, has first-hand knowledge of the impact

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caused by the lack of a burn unit in Coahuila. In 1997, he was severely burned and rushed to a local hospital in Saltillo, Coahuila's capital city. Since the hospital didn't have a burn unit, his family had to make arrangements for treatment in Galveston, Texas, which meant losing crucial early treatment time.

Once the choice was made to award the tank to Coahuila, Ariel began speaking to Luis Antonio of the State of Coahuila Government (<http://en.coahuila.gob.mx/geo/htm>) about donating the medical equipment. Luis, a burn survivor, was naturally receptive to the idea and arranged a meeting with other government officials, including Coahuila Governor Enrique Martinez y Martinez. The Mexican government agreed to accept the tank in April 2004, but arrangements had to be made to transport the tank from California to Mexico.

This has been accomplished through contacts in the burn community. Michael contacted Leo Bisordi, an operating manager for the Georgetown, California, branch of HA Logistics, Inc. (<http://www.halogistics.com>), who was willing to ship the tank to Eagle Pass, Texas. I contacted Boyd Applegate, a California truck driver and burn survivor, who, along with his brother-in-law Ted Norman and co-worker Steve Gothman, donated their time to transport the tank to a warehouse to await delivery to the Mexican government.

**BSTTW**, through its tireless founder Michael Appleman, is currently working to improve care for burn victims in Africa, Argentina, Canada, Egypt, France, Ghana, Guatemala, Hong Kong, India, Iraq, Mexico, Pakistan, Peru, Slovenia, Spain, the United Kingdom, the United States and Vietnam. You can learn more about the recovery of Michael and Ariel and their music CD collaboration at <http://www.burnsurvivorsttw.org/articles/bsttwsong.html>.

## The Pride of A Burn Survivor

By: Richard (Iron) Baayeh

One and half years of waiting to receive award after the GHAPSA (Ghana Polytechnics sports Association) Games held in Cape Coast – the town noted as the ancient route for sub Saharan slave trade, I was astonished and delighted to note from the polytechnic's sports secretary that the trend of giving certificate as award of merit has changed and that the association has decided to switch to the use of medals though not pure Gold, Silver and Bronze.

“Be this as it may, I present to you, your medal for achievement in the last GHAPSA games in the Discus throw” said the secretary. Standing in front of his office desk and seeing the medal wrapped in a colorless but thick polyethylene, “yes” I shouted triumphantly, then he gave me his hand and so I gave him back my hand and he shook it heartily and with great pride and cordiality. Then he wished me well in my future endeavors.

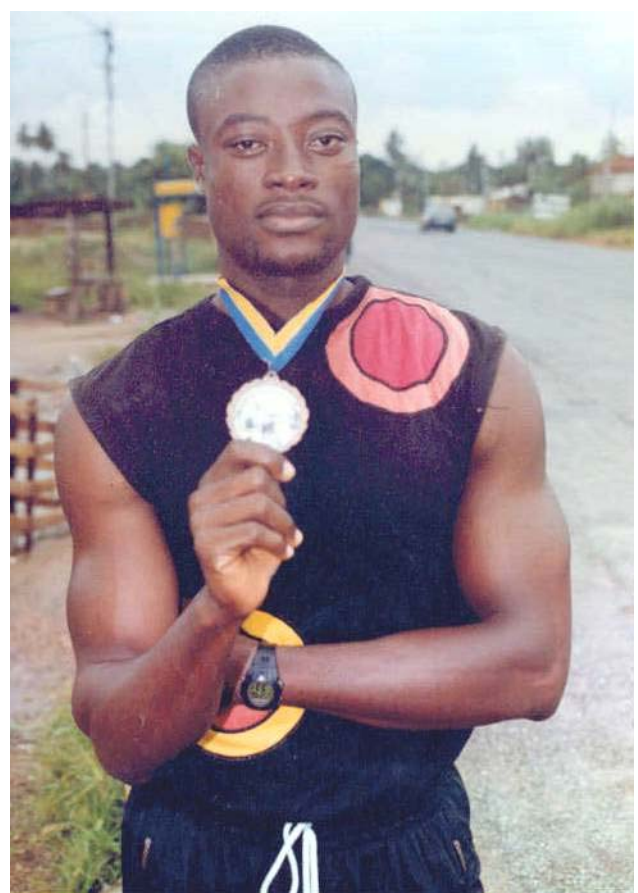
Then I thanked him sincerely for his positive thoughts towards my future and me. As I walk out of his office, I walked softly as if the dead could be disturbed. I became perfectly delighted. I walked shoulder high in school with the medal dangling around my neck knowing very well that as a burn survivor I have achieved what my schoolmates could not. This made me feel big inside.

The receipt of this medal took me down memory lane as I remember my infancy, my grandmother, my mother and I had always lived by ourselves in the happiest state imaginable, and lived so then, and always hoped to live so. But I still want to run and not throw.

The award though not big in terms of recognition, is an excellent morale booster for bigger things to come. I am force to imagine how it would all be like in the burn survivor's community to note that a burn survivor has won a medal in major athletics meeting. For me it would be the greatest prides for all burn survivors. It would be a victory over fire and for that burns but, in the mean time, I sincerely and

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honestly dedicate this medal in my modesty to all Burn Survivors Throughout The World, Inc.. God Bless this dream. God bless BSTTW.



Above is Richard (Iron) Baayeh wearing the gold metal that we worked so hard to win after suffering severe burn wounds to his legs. Richard is an example of a burn victim who fought to not only become a burn survivor but to reach goals that many people felt where a dream and would never become a reality. We all can move forward in our life after suffering a burn injury. All of us must work towards accepting the fact that as a burn survivor our lives have changed, our lives are not over and that we are not alone.

## Vanished Smiles

By: Shirin Juwaley

Seated in the cyber-cafe, literally I'm getting baked in the heat. Can hear the humming of the air conditioner but the air seems to be stuffy and hot. The geeks sitting besides me seem to be totally oblivious to the heat as they are entranced by the colorful screen that is teaching, educating and making them thirsty for more.

Last night I met a college buddy at the cyber-cafe. He was sitting on the cash counter. As I was exiting I happened to glance at his face and instantly recognized him. I called out this name and he seemed totally lost of my identity. After giving him my name he could make some sense of it. He was totally flabbergasted to see my badly burnt and disfigured face and simply did not know what to say. I explained him about my accident and I strongly feel that he hardly must have registered anything in his brain as he was still reeling from the shock. We parted with goodbyes but somehow the parting seemed very incomplete.

As I walked home, faces flashed in front of me of those who had always given me a smile of recognition. All those smiles today have vanished from my life. People like the florist, whom I would buy my flowers, my baker, the grocery store attendant, the fish monger, the fresh produce monger, my teachers, my distant friends, my relatives, people who knew me as a child, all fail to recognize me. I have lost all those smiles that took years to be achieved.

Truth is, sometimes I miss my face. There are times when I simply want to be unnoticed like everybody, without the sneers, and pitiful sighs. When I travel by bus 9 out of 10 people refuse to sit next to me. Sure that one person who does not care about my looks matters!! but... think about it... I have to face 9 rejections to be able to be accepted by one person! To tell you the truth, it hurts. Sure being burnt was the best thing to happen to me but sometimes doubts creep in to me. Sure I'm positive, courageous and blah, blah, blah but there are times when I want to be like other girls. Flaunt my looks and talk about men and giggle and act absolutely

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foolish. When it boils down to reality all this is not for me. I suppose I've lived my life, but giving up on worldly things can be very strainful. Being content all the time needs a lot of strength and fighting with your emotions can be very hurtful.

The amazing thing is that despite of all heartaches and pains and tortures of life, we humans thrive, we live and we prevail.

Love you all,  
Shirin

## Caregiving: Recognizing and Prioritizing

By: Dr. Debra Moore, PhD.

### STEP 1 RECOGNIZING AND PRIORITIZING PROBLEMS

This may sound simple, but it's not always easy to tell when something serious is happening to aging parents.

Especially if they do not live nearby, and you are communicating by phone and occasional visits.

Family members may not even know they need help. And many older people are too proud to ask for help.

Even if your parents are getting medical help, they may not be diagnosed accurately.

Or they may have multiple physical problems, each one being treated by a different doctor, who is prescribing medication but not aware of what other physicians are treating or medicating.

This 1st step is getting to where you "see" what is happening with your parents.

In addition to whatever specific conditions are involved, there are 5 other important factors which affect your ability to recognize problems:

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You and your view of the world:

You will be much more effective as a caregiver if you know yourself well.

Do you have a realistic view of your personality traits, your strong points, and your weak areas?

You need to know your "hot buttons" to avoid having them pushed.

If you don't know yourself, you will project your own feelings onto others and you will think you are being objective when you really aren't.

For example, if you are overly optimistic, you may discount your parents' worries and problems.

If you are resentful of your parents, and not aware of it, you may attribute their expressions of pain to whining or chronic complaining.

A fear of death may lead you to avoid necessary conversations or decisions.

Knowing yourself means recognizing & accepting a range of feelings as legitimate & getting past them.

Listen to yourself when you talk about your parents - the clues are all there.

Your fear of aging:

Caring for a parent forces you to confront your illusion of immortality.

Aging, disease, and death cease to be abstract concepts.

We become more aware of the rapid passage of time and our own aging.

Most of us have been trying to use denial as much as possible.

There's the story of the young woman who asked God to grant her 1 wish - to warn her

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when she was approaching death, so that she could prepare for it.

The years passed and the young woman grew old and gray. Finally one night she passed away in her sleep. She arrived in heaven and demanded an audience with God. You promised! , she said, "You let me die in my sleep with no warning!"

But God replied that he had kept his promise and that he had given her many warnings... "Warnings?" she said, "You gave me no warnings!"

And God simply replied, "Look at your gray hair, your wrinkled skin, the way you bend when you walk and how easily tired you become. How did you miss so many warnings?"

Your knowledge about health and aging:

Aging is not a disease. But the aging process is often complicated by health problems.

Older people are not really different from younger people, but they are much more complicated!

Contrary to myth, most older people respond well to medical interventions, medications, and even surgery. Refer to the handout for more info on danger signs and how to work with your parent's doctor.

Your motivation to care:

Motivation to care for an aging parent is influenced by many things, but 6 factors are common.

Love.

Equity. A sense of owing your parents something, paying them back for their years of caring for you. This can work the opposite also if you did not feel cared for as a child.

"Why should I help her? She was never there when I needed her."

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Equity means what we think is fair and just. It is a very personal decision and others may disagree with your thinking.

Morality. This is a conscious awareness of what society and others say is proper. Doing what is expected can be a strong force. Sometimes parents or siblings will use this to influence you.

Ethics. This is your own inner sense of right and wrong. It may conflict w/ the ethics of your parents.

Envy. Many adult children envy the love and respect their parents seem to have for their siblings. If this is you, you may try to earn your parent's love by outdoing a sibling in caregiving. It is as if you are trying to "capture" your parent.

Greed. An expectation of material gain.

These motivations are not independent of each other. It's human to experience any or all of them.

The challenge is to recognize them and figure out how they influence how you give care.

**BSTTW COMMUNITY NEWS****BSTTW POEMS****Is There Still Hope?**

By: Jeremy Robinson

You're gone  
I've lost you for now  
But I'm not gonna quit trying  
To figure out how  
To get you back in these arms of mine

There isn't a thing I wouldn't do for you  
I just need on more chance  
Cuz girl you had me from the very first glance

There isn't a person in this world  
That could ever take your place  
One look at your face  
And I'm floating in space

The silence will be broken  
More words will be spoken  
Until you decide to take me back  
Girl you're everything I lack

*Jeremy Robinson*

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)



## 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 941-364-8457 or toll free at 800-503-8058. 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**, **BSTTW Ho Tu Tu 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.  
650 N Beneva Road #305  
Sarasota, Florida 34232

#### **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 941-364-8457, toll free at 800-503-8058 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 941-364-8457 or toll free at 800-503-8058.

**BSTTW ADDRESS & PHONE NUMBERS:**

Burn Survivors Throughout The World, Inc.  
650 N Beneva Road #305  
Sarasota, Florida 34232  
(941) 364-8457  
Toll Free: 800-503-8058  
Fax: (941) 364-8441

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)