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# BSTTW COMMUNITY NEWS

Volume 5 Issue 3

July 2005

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## BSTTW REBUILDING LIVES

### Thanks To The Profile Manger

By: Michael Appleman, CEO

**B**urn Survivors Throughout The World, Inc. (BSTTW) is an international 501 (c)(3) non profit organization. BSTTW works in many areas of the world offering face to face support, medical referrals, medical supplies, medications and support groups. BSTTW is currently working in Africa, Argentina, Canada, Egypt, France, Ghana, Guatemala, Hong Kong, India, Iraq, Mexico, Pakistan, Peru, Slovenia, Spain, the UK, the United States and Viet Nam.

BSTTW also offers one of the top internet sites to the burn survivor community and the public world wide. Our internet site offers burn survivors and family members a support team, advocacy, membership and education. We also offer the information needed by the public to help increase their education relating to taking part in rebuilding the lives of a burn victim and fire safety.

BSTTW needed a program that would help BSTTW keep track of our members and also offer the burn survivor community a family like atmosphere. I searched the internet and found Profile Manager. It looked and sounded like the program we were looking for. I downloaded the free version and gave it a try. The profile manager worked great. We got an excellent response from the burn survivor community. The areas that members were asking

for was only in the premium version of Profile Manager. I knew that BSTTW and our members needed the upgrade. The problem was that BSTTW was in the process of raising money to transport medication and medical equipment to different areas of the world. We also had several burn victims that were in need of free medical care. The BSTTW board of directors felt that we could not pay for the upgrade to the premium version due to the fact that the money spent for an internet program could be used to help a burn victim get medications and/or medical attention. I decided not to give up hope and contacted Interlogy Internet Technologies, LLC (IIT). I spoke to Aytakin Tank from IIT and explained BSTTW's situation and the work we are doing to save lives and asked for their support. Mr. Tank reviewed BSTTW and informed me that IIT was very interested in the work that BSTTW was doing to help rebuild the lives of people who suffered a burn injury. Mr. Tank also informed me that IIT wanted to take part in helping not only BSTTW but the burn survivor community. The Profile Manager Premium version was donated to BSTTW. Immediately I

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## A FAMILY AROUND THE WORLD

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upgraded the site and informed our current members, email lists and others about our new membership. We received a very positive response.

I would like to tell all of you that are reading this article that the Profile Manager Premium program offers the webmaster and the registered members options that most other programs do not. Your members are protected, you have a choice to accept or deny membership and control existing member's actions.

With the use of the professional version, BSTTW was able to offer our members the availability to search out other burn injuries that had similar burn injuries and family members are able to find other family members. Both burn survivors and family members can contact each other in order to not only gather the support and information needed but to also make new friends. All of our members can also upload pictures, visually see what each other looks like and meet each other in a private and secure chat room.

Below are a few quotes from our members:

1. “Before we only filled out an e-form. Today after the e-form is sent, we go directly to the membership sign in. I signed in and it was great to see a list of o their members that I could talk to.”
2. “I was so happy to receive an email from another member. This helped me to feel that the support was truly available.”
3. “Since the membership is private, I feel more secure uploading pictures for others to see.”

The BSTTW board of directors would not only like to publicly thank Aytekin Tank and Interlogy Internet Technologies, LLC, BSTTW would like to suggest that other groups, non profit organizations, elist groups and companies purchase the Profile Manager Premium program in order to offer your members and clients a stable and secure membership area.

**BSTTW COMMUNITY NEWS****Nothing Is Impossible To A  
Willing Heart**

By: Monika Sethi

The greatest power that one possesses for succeeding in life is our understanding that life **gives** you a fresh start at any moment that you choose to begin again. No matter what has happened, in your life, and how strongly it has affected you, you must always have to remember that nothing that stood in your way would remain there for long and that it cannot stop us for long. When things change in your life, we hope that all of the changes are for the better. Depending on the situation as humans we cannot always realize everything will turn out for the good. But do not worry with positive thoughts and help from others, it will not remain there forever.

Maybe it is very easy for some of us to just say it. As a burn survivor, I personally know that working through the rough times is not easy. I like so many others, had to drag myself out of the depths of the deep and painful despair. I found out that the negative emotions had a negative effect on my burned body. When that was finally realized, I decided that it was time to get rid of the negative feelings and live in a more positive way. As I began to make this very important change, I found out that positive emotions have a positive effect on my life. What a great feeling that was and still is today.

As I burn survivor, I have had to deal with the physical and emotional scars that I suffered. This is the biggest insult that I thought I and any other human being could endure. I suffered through the moments of emotional ups and downs. Each and every negative emotion caused me to physical pain somewhere in my body. During the pain, I fought within myself to trust fundamental ability of fighting against all odds! That helped me to find the strength and help needed to not only live but to live a life of dignity and self respect.

Most of us need love and respect from ourselves and others. It is in the giving and receiving of love and respect that we choose

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 life. The greatest power that we all possess for succeeding in life is our understanding that life gives us a fresh start any moment we choose to start fresh. If we feel that the love around us is not bringing us where we should be or we are finding a gap in our lives then you might want to look for spiritual guidance.

Spiritual guidance is not restricted to one area, or one particular day or time of the day. While we may be more open to receiving spiritual guidance in the quiet hours of the early morning, or the late night, we need to understand that spiritual guidance is always present. It is present in books that we 'happen' to come across, articles that we reading and things that we hear. Many times that new information is applied to our personal situation.

Perhaps if we expected to receive spiritual guidance at each and every moment of our lives instead of simply in church on Sunday, or when we sit quietly in meditation, we would receive many more messages throughout the day. On the other hand what if we need that spiritual guidance and the end result of the situation is still negative. We need to learn from that experience and then move forward again in our life. This will allow each and every one of us to gain strength and positive ideas.

So dear friends I personally ask you to do what is needed and Live for today. Celebrate the past, embrace the present, and anticipate the future. Learn from the past but don't live and dwell on yesterday. Recognize that the good old days are never going to return and maybe they were not as good as we recall them to be. It would be best if you make sure to engage fully in this day so you can provide yourself with love, positive thoughts and the happiness of being a burn survivor and not a burn victim.

As a burn survivor, I can understand the pain that you all might be going through or have gone through during your life. The most important thing that I do know is that if I was able to find what is needed to become and remain a burn survivor, you can do the same.

## **BSTTW COMMUNITY NEWS**

Something that you should always remember is that suffering a burn injury or any other accident during your life, you are still alive. You did not loose our life. If you have not realized this yet, I ask you to please search within yourself, and find your purpose in life. Whatever that purpose is, you need to reach that goal. Do not allow the pain, the burn or any other type of injury to stop you from accomplishing that goal! If you worry, you are allowing the negative ideas and emotions to take control. The end result is negative. The only changes that this can make, is for you to take steps backwards.

To worry is a total waste of time. It may change things for a few seconds but when you come to terms with reality you realize that this did not change anything. All that negative emotions and thoughts, worry does is taint your mind and steals your joy. So open your arms and welcome today. If you are in pain emotionally and/or physically reach out to a friend. A true friend will grab you hand and help you in any way he or she can. We must all come to terms with the past and let it go. We should keep the past in the past. Remember that when the going gets rough you must find the strength from within yourself and fight back. Don't lay back in pain or distress because nothing is impossible to a willing heart. Move forward, recover from the injury and find your new path in life.

**Each step a challenge  
 Each day a joy  
 An unstoppable spirit  
 None can destroy**

**The worst you know  
 Is yet to come  
 To create awareness  
 This must be done**

**You have the reach  
 To change perceptions  
 And take the search  
 In new directions**

**And then emerges  
 wondrous things  
 That restores your life  
 within seven springs**

## Fire Safety Versus Clean Air

By Delores Gempel Lekowski  
Author of The Hurting Angels

Would you risk a 3<sup>rd</sup> degree burn for clean air? Should we disregard fire prevention in order to meet the clean air standards? The California Air Resources Board (CARB) and the Environmental Protection Agency (EPA) seem to think their goals are more important than our safety and believe that the dangers of fire and burns would be a small price to pay for clean air.

To cut down on small engine pollution CARB and the EPA will require all off-road engines with 50 or less horse power to have catalytic converters, this will include lawnmowers, weed whackers, chain saws, leaf blowers, generators and small boat engines. If grass ignites at 518 degrees Fahrenheit and catalytic converters can get to 1,151 degrees Fahrenheit, doesn't common sense tell us to keep catalytic converters off the grass? And who in their right mind would want to hold something in their hands that is 1,151 degrees hot?

Fires have been reported when cars with hot catalytic converters parked on the grass or leaves, if this could happen from parking a car on the grass, think about what could happen when you run a lawn mower over dry grass and with your legs and arms only inches away from this tremendous heat. I guess after this takes effect we better watch where we park our lawn mowers, gone will be the days when you could just roll it into the garage and forget about it. What could they possibly be thinking? It seems to be a "take your chances so you can breathe deeply," mentality. It doesn't matter how we meet the clean air standards just so we meet them.

I want to make it perfectly clear that I am 100% behind fighting for clean air, but I am not willing to take this risk and we shouldn't be forced to take it. The price is too high. While we all have the right to clean air we also have the right to be protected from harm or death, trading one for the other is never an option nor should it be.

## BSTTW COMMUNITY NEWS

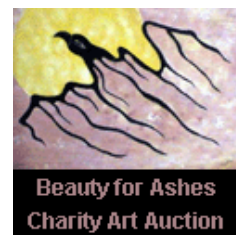
The list of those who are concerned about this addition to the Clean Air Act is compelling and will lead one to believe that this is not a positive step towards clean air but a dangerous trade off.

Below are some of the groups or individuals who oppose the catalytic converters for small engines. It is their consensus that CARB failed to provide evidence that the small engine converters would not pose a fire hazard.

- 1-National Association of State Fire Marshals
- 2-Consumer Products Safety Commission
- 3-Missouri State Fire Marshal
- 4-National Marine Manufacturers Association
- 5-Senator Christopher S. Bond R-MO
- 6-California Fire Chiefs
- 7-California State Fire Marshals

You may read more about this and Senator Bond's objections at the, "Project Vote Smart," web site. Here, his views are compelling and as with all of those who have fire safety concerns about small engine catalytic converters, he brings up their very valid points.

*Beauty for Ashes Charity Art Auction*  
TAKE PART WITH **BSTTW** AND RAISE THE FUNDS NEEDED TO REBUILD THE LIVES OF OUR CURRENT & FUTURE BURN VICTIMS AND BURN SURVIVORS



The **BSTTW** Beauty for Ashes Charity Art Auction on eBay Giving Works is from June 7<sup>th</sup> through June 21, 2005. Over 100 artists from the Worldwide Women Artists Organization (WWAO) has started the Beauty for Ashes Charity Art Auction in order to join **BSTTW** and rebuild the lives of our current and future burn survivors. These artists understand, care for and love everyone who suffers a burn injury. **BSTTW** and the WWAO asks you to take part in this auction.

## Survey to Measure Satisfaction with Internet Social Support Following a Burn Injury

By: Cheryl Inmon Long

You are invited to participate in a study about the everyday social experiences, sources of support, and coping strategies among adult burn survivors. If you are a burn survivor at least 18 years old, you are invited to participate in the study.

- It is my hope that results of the research will provide burn professionals and the burn support community with important information about the types of support that adult burn survivors find helpful when dealing with everyday situations.
- By types of support, I am referring to support from Internet resources (like burn support listservs, chatrooms, burn support websites, etc.) or in-person types of support (like from family members, in-person burn support groups, friends, etc.).

Participation is completely voluntary. I will not ask for your name or for identifying information. The survey will take approximately 20-30 minutes to complete. Your answers will be combined with the answers from many participants and will be reported only in a group summary [for example, "more individuals liked blue than red"].

As a token of appreciation for participating in the study, you will have the option of entering a drawing for one of four \$40 gift certificates to Amazon.com. You will also have an opportunity to request a summary of the results of the study. To enter the drawing or to request a summary of results, you would need to provide either an e-mail address or a mailing address in order to receive the gift certificate if you are drawn or to receive a summary of the results. Your address in this case would only be used for the purpose of the random drawing and/or to receive the summary of results and would not be linked in any way to your answers on the questionnaires.

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Please be assured that there will be no way for me to identify you.

To participate in the study, please go to <https://www.psychdata.com/surveys.asp?SID=9369>

or alternatively, go to <https://www.psychdata.com/> and enter "9369" where it asks for the survey number. *If the survey does not open automatically, please click the "click here" directions to open it.*

If you have questions about the study, please contact me or my advisor Robert Nutt, Ph.D. at the e-mail address or the phone number below.

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Advisor: Roberta Nutt, Ph.D.

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 **BURN SURVIVORS  
THROUGHOUT THE WORLD**



**BSTTW is part of the Local Independent Charities of America, United Way of Lee County Florida and eBay Giving Works.**

## Advocacy - A Wellness Tool

By: Mary Ellen Copeland, MS, MA

To truly experience wellness and recovery I have learned that I want to be, and have to be an advocate for issues that I feel passionately about. A big part of recovery for me has been learning to advocate for myself. When I began work on my recovery, I had no idea how to ask for what I wanted, needed and deserved. I don't think I even knew what it was that I wanted. Over the years that has changed dramatically. I have become a seasoned self advocate. I know what I want for myself and work on it until I get it, or until I decide it is really something else I want and start working toward that. From time to time I have advocated for another person or a program. But now, with major cuts proposed in programs that are very important to me, and with the focus of our government being oppositional to many of my beliefs, I have become convinced that I must become a strong advocate in my community, region, and even nationally.

As I have gotten more and more involved in this advocacy work, I have discovered that for me--perhaps not for everyone--advocacy is a wellness tool. I need to include it in my TOOLBOX of things to do to keep myself well and to help relieve symptoms if I am feeling badly.

How did I discover this? Usually by January I am fighting to keep seasonal depression at bay. This winter that was not so. Today, as I write this column. It is March 1 and I realize I have missed my mid winter depression. Why? I think it is because I have been working hard on a public issue that I feel passionately about. I have called and written officials at all levels, I have gone to public meetings and spoken out--even when I knew my views were strongly opposed. I arranged a public education meeting that drew so much attention to the issues that there were front page stories in our two newspapers and a radio interview. The phone keeps ringing off the hook. Everyday there are arrangements to make. I call people I thought I would never have the courage to call. I even

## BSTTW COMMUNITY NEWS

had a dialogue with the governor on interactive television.

I hope advocacy is a wellness tool for you as well because we are all moving into a time when the things that have been most helpful to us in our recovery--programs, services and technical assistance centers--are being threatened with cuts or loss of funding. I get at least one e-mail every day about troubling cuts of effective programs that benefit all of us. Our governments don't seem to realize that it is much more cost effective to provide supports to our recovery, than to pay exorbitant costs as we go into crisis again and again and again. We all need to do everything we can to insure that the funding for the programs we find most helpful is not cut or eliminated. The more of us that speak out, the more likely it is that we will be heard.

Begin by thinking about those services that have been most helpful to you. They may be mental health services, vocational rehabilitation or it might even be your local library or an adult education program. Then be watchful. Read your newspaper, Listen to the radio. Talk to your peers. Read your e-mails. If things that you care about are being threatened with cuts, make a commitment to do something about it. If officials hear from enough people, they can change their view and their vote.

Get together with others--friends and community members-- who have similar concerns and work together to develop and implement strategies to influence the people who make decisions. Set a time and place to meet, call several others that you know are concerned about this issue, ask them to come and bring along several friends. You may decide to make calls, do a mailing or set up an informational meeting. If you are lucky, others in the community may already be working on this issue and you can join their efforts

You could begin by making phone calls. This is not as easy as it sounds. You may be, as I was, a bit reluctant to call someone you don't know. Try to let go of these fears. Figure out who it is you need to influence and give them a call. Perhaps it is a town or city official, your

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legislators, the governor or even the president. It's scary the first time you do it. If the person you are trying to reach is not in, leave a voice message asking them to call you back. If they don't call you back, call again the next day. Keep calling until you have a chance to tell them how you feel about these cuts. Ask them to keep you posted on what is happening with regard to this issue. Call them back when you have new questions or concerns. Keep your calls brief and to the point.

Send letters and e-mails--even if you don't feel you are a good writer--clearly stating your case. I have been told that officials pay more attention to letters, but if all you have time for is a quick e-mail, go ahead and send it.

A fax is an excellent way to get attention. Again, make it brief and to the point. Don't use too many words or people won't bother to read it. For instance, if you are concerned about threatened cuts of technical assistance centers you might fax your congress people (you can get the fax numbers by calling their office) and say: Please use your influence to assure continued funding of the technical assistance center in any city, any state. This center has promoted the recovery and wellness of thousands of people at great savings to the mental health system. Or, I had not been able to hold a job for over 20 years. This center gave me needed skills. I now work over 20 hours a week. If the food stamp budget is being cut you might say: Do not cut the food stamp budget. I lived on the streets for over five years. If it weren't for food stamps, I would have starved. I now have a good job and am able to take care of my own needs.

Go to hearings. During the breaks, let officials know why you are there. If there is a chance for you to speak, go ahead and do it--even if you feel very scared and have butterflies in your stomach. Everyone goes through that. This is too important. Just do it. It gets easier each time you do it. Again, keep it brief and too the point. Everyone gets bored and stops listening if he/she goes on for too long. Afterward, give yourself a nice treat--like lunch with a friend or night at the movies.

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Perhaps someone is organizing an action of some sort--like a march to a public building or standing on a street corner with a well worded sign about the issue. Maybe you are on the committee or in charge of the committee that is organizing the action. Actions are a great way to let others know how you feel while being supported by your peers.

Avoiding winter depression is not the only benefit I have noticed of being an advocate and speaking out. I notice that my self esteem, self confidence and self respect have been all gotten a "shot in the arm". I feel less stressed because I know I have done what I can. I have met and worked closely with many wonderful people. My circle of supporters, friends and acquaintances has grown. I feel much more connected to my community. And I have created some change in the world. All in all the payoff is great.

## BSTTW POEMS

### Willing To Live

By: Michael Appleman

After suffering the injury that day  
I did not think I was hear to stay

My life appeared to be over  
The burned skin and body was an open cover

The pain and emotions were lost in space  
Was I going to be able to win this race?

I felt that time was not on my side  
This was a very rough ride

Never did I think that burns were so bad  
All of my family looked very sad

Each time I wanted to move around  
They all heard me yell a very loud sound

After years of recovery I am happy to say  
I am alive and with you all today

A burn survivor I am and happy to be  
With support I am alive, together and free

*Michael Appleman*

I wrote this poem in order 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. Remember that BSTTW has a support team that is on call 24 hours a day, seven days a week. You can contact the **BSTTW Support Team** at [www.burnsurvivorsttw.org/eforms/supportemail.html](http://www.burnsurvivorsttw.org/eforms/supportemail.html) or if this is an emergency you can fill out the **BSTTW Emergency E-Form** at [www.burnsurvivorsttw.org/eforms/emergemail.html](http://www.burnsurvivorsttw.org/eforms/emergemail.html) or by telephone at 800-503-8058.

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I found the help I needed during my recovery and that is what allowed me to not only recover but to start **BSTTW** in order to help other burn survivors and family members.

*Michael Appleman, CEO*

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/poemaker.html](http://www.burnsurvivorsttw.org/poems/poemaker.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 Viet Nam 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)