
BSTTW TEEN NEWS

Volume 3 Issue 4

October 2003

BSTTW OPENING DOORS

BSTTW WBC Get Together Dinner & Video Voice Chat

By: Michael Appleman, CEO

BSTTW had their second WBC get together dinner & video/voice chat at the WBC 2003.

On September 11, 2003 **BSTTW** members met in the lobby of the Renaissance Cleveland Hotel. Together we decided what local restaurant we would like to go to. When we arrived at the restaurant, the restaurant representative informed us that **BSTTW** needed to make a reservation several hours in advance. I explained to her that this was a special get together and we would like very much for them to set up a large table for us. The manager of the restaurant came to our rescue and stated that there was a private meeting room available. The meeting room had a large table for the twelve of us that attended the dinner. With a vote of hands, we decided to wait for the room.

When we got to the meeting room, most of us were very hungry. But again we had to wait for the waitress to get set up. That was ok since we all looked around and felt relaxation and a strong friendship growing. We talked and joked about life. After ordering and getting our food we saw that 2 1/2 hours went by. I looked at everyone and said "the time really went by fast". It is much nicer to have time fly by when you are

relaxed and enjoying life. Remembering back to the days, weeks and months during our recovery, each second of the day felt like it stood still. Today life is so much different. Even with all the changes from

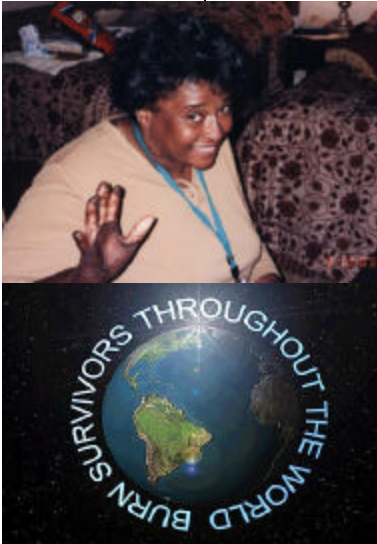
before we were all burned, life is enjoyable, relaxing and special.

After the dinner most of us went back to the **BSTTW** hotel room to take part in the annual **BSTTW** WBC 2003 Video/Voice Chat. We signed into ivisit.com and found that many burn survivors/family members were waiting for us. They were so happy to see our faces and hear our voices. By shifting the web camera around the room, they were able to see us all.

After speaking with us, the grandmother of a burn survivor, Julieanne, began looking into setting up a trip to the USA in order to attend the WBC 2004 in Chapel Hill, North Carolina. She was very interested in

taking her grandson, a teenage burn survivor, to the event. Once we signed off the internet, Julieanne, called the **BSTTW** hotel room to speak with us. She was still very excited and wanted to continue hearing our voices.

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A FAMILY AROUND THE

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The WBC is the time when burn survivors, family members, doctors, burn units, care givers, attorneys and others from around the world get together to get & give support, learn and just enjoy several days together. At the WBC so many burn survivors and family members open up and release the pain and suffering that has been inside of them since the accident occurred.

Back in 1999, I attended the WBC for the first time. At that time, I was unable to walk or use the left side of my body. I had suffered from 1st, 2nd, 3rd and 4th degree burns. My recovery lasted years. During that time, I had surgery, suffered heart attacks and strokes. My body and mind had changed. I did not know what my life was going to be like. After meeting so many caring burn survivors, I realized that life was not over. There was a chance for me to recover and have a better life.

BSTTW has a WBC Donation Fund in order to gather the finances needed to help other burn survivors attend the WBC, have our WBC dinner and chat, offer information at a WBC booth and help offer the information needed for the burn survivor community to get the donations needed to attend. Please take the time to go to review our internet site at www.burnsurvivorsttw.org/wbc.html in order to find out more about the WBC, see pictures of the events and hopefully decide to donate to the BSTTW WBC Fund.

If you have any questions or need information in order to help you get the funds needed to attend the WBC 2004 you can contact BSTTW at wbc@burnsurvivorsttw.org or at 800-503-8058.

Still Burning Today

By: Petra Zigon

My name is Petra. I am 23 years old and I live in Slovenia. I found your address on the internet, and it has given me new hope.

At the age of 9 months, before I had begun to walk and talk, I experienced a bad accident. The handle of

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a hot coffee pot my mother was holding broke and the boiling coffee spilled all over me. I was very badly burned on my left arm and left leg. I feel as though my little child's world was changed by the scars I had received.

Although so much time has gone by since then, I still remember the white doctor's uniforms, the strong lights and the terrible pain. I was hurt and frightened. I cried a lot while my left arm and leg were healing. And that was not the worst of it. Later on in life, I was never accepted by other children. They always treated me with derision and isolated me, giving me the feeling that I was different and inferior to them. I yearned for the company of children my age, and to be accepted by them, but it remained an unfulfilled yearning. The same story repeated itself again and again as I was growing up. It even went so far that I stopped wearing dresses and tops with short sleeves, because I had the feeling that I was irking everybody with my scars. My self-confidence was practically non-existent and I lost all aims in my life, although I was a good student. When puberty came, I started overcompensating to a great extent because of my scars. The most important thing to me was that I should be perfect in every other physical aspect to compensate for my obvious shortcoming.

At the age of 15 I was operated upon again. The surgery was done in order to help hide my scars. I felt that hiding my scars would help me to feel more positive and others would not stare at me anymore. Unfortunately no scalpel can cure the internal scarring that remained along with the traumas. During that time I was also severely bullied at school, My lack of self-confidence offered me as an easy target. When I was 17, my father, whom I was very attached to, also died suddenly of a heart-attack and my whole world collapsed.

The internal scars remained and only intensified the loss of my father. I was left without the strength or the will to finish my secondary school degree. I also found that I was living alone without true and honest friends. I would like so much to get out of this traumatic labyrinth, to live a normal life like all the

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other girls. This way I can experience and accept the world and my scars and for the world can also accept me.

In Slovenia we do not have such experienced counselors. I feel that America can offer more for people to get the help needed in order to recover from such a traumatic injury. True, in Slovenia, there are brilliant surgeons and experts in the scientific fields, but in human contact and in offering support, they have a long way to go yet. This is a very big reason why I was not given the counseling when I was young and also today. There are no burn survivor support groups in Slovenia.

I am very happy that I was able to find BSTTW and begin to get support and meet honest and caring people. Michael Appleman, BSTTW's President, spoke with me and my family. I asked Michael if there is any way that he could help me, or advise me. I also said that I would really like to start living a normal life and would be most grateful for any assistance that he and BSTTW could offer me. Michael and BSTTW offered to have himself and a member of the BSTTW Support Team meet with me and my family on the internet in a private BSTTW meeting room. He said that the BSTTW support team would help offer me and my family the support needed in order to begin to find my new life. I and my family said yes to that offer and today we are very happy to know that people are there to support and care for us. The BSTTW support team is also available for emergencies. They have been able to get back to us in 24 hours or less.

BSTTW has helped me to at least know that other people understand and care what happens to me.

Thank you Michael Appleman, BSTTW and your support team.

The WBC and Me!

By: Delores Lekowski

Never attended the World Burn Congress? Put it on your must do list for next year.

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What you will walk away with will far exceed your expectations. This is how I viewed the experience.

If you want to meet the nicest people in the world, surround yourself with burn survivors. If you want to feel an unexplainable energy, hang out with a burn survivor. If you want to be a part of raw courage, make friends with a burn survivor. If your life seems to have no meaning, let a burn survivor enlighten you. If you find it hard to forgive, ask a burn survivor how they forgave. If there is no meaning in your life, see what life means to a burn survivor. If you have lost your purpose and what is important, really important in your life, let a burn survivor tell you their story.

Inadvertently, we did this to everyone we came in contact with at the World Burn Congress. Without knowing it, we touched everyone from the desk clerks to the maids in our hotel to the people we had contact with in Cleveland. I am not just saying this, I called the Renaissance Hotel yesterday and talked to the General Manager to thank them for a job well done. The General Manager told me many staff members commented on what an awesome group we were and what a great experience it was for all of them. Yes, we made a difference. And what we survivors did for each other can't be put into words. We have a sacred bond to each other, a bond that outweighs and overpowers any bond humans have for each other. We were strangers and at the same time we are partners. We have shared the same pain and the same grief, the same triumphs and the same setbacks. We have given the true definition to the word courage, a definition that few can remotely understand. We are burn survivors, we are the best. If I sound arrogant, your right, I am and because of all the reasons mentioned above, you also have permission to be arrogant. But enough about us, lets get to the WBC.

I would like to tell you about my experience at this gala event. I didn't arrive till Thursday and I left on Friday so I missed the grand opening ceremonies and the closing banquet but I don't feel as if I missed a thing because of the new friendships I acquired and the old ones I renewed, I felt both days were a ceremony. You always feel welcomed and you are

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always in the best of company at the WBC.

After attending various sessions of my choosing, I hung out at the lobby or lounge as this ended up being the place to congregate. Michael Appleman had previously through emails, invited everyone to a Burn Survivors Throughout The World, Inc. (BSTTW) get together dinner with him and the BSTTW Vice President, Director – Viet Nam his wife Dieu Tran. I have talked to Michael via phone calls and emails but this was the first time we met in person. Michael is one of those people you automatically like and you can tell right off the bat that he is a leader of people. Dieu Tran is a very sweet caring person, this was evident when we went to their room after dinner to participate in the BSTTW WBC Video/Voice Chat. She offered us sodas and her homemade sweet rice cakes while she made sure we were comfortable. Oh! I want to throw in an interesting tidbit here. Mr. and Mrs. Appleman had a mystery door in their room, a door that went no where, was it a door to the world? That’s kind of fitting, after all the WBC is also a door to the world.

Let’s go to dinner! We decided to go to a place called something Q’s or was it J Q’s? There were 12 of us. The food was good, but pricey, and the service left a lot to be desired. The nice thing about the slow service was we had three hours to get to know each other and for me, this dinner was one of the highlights of the WBC. After making the waitress angry because we failed to tell her the checks were separate and having an automatic 17% gratuity tacked on our checks, we courteously paid and went back to the hotel.

The next day we attended the various sessions, these sessions are always informative and give answers to most of our questions, but most of all, they offer a unity to burn survivors. In between sessions we always found the time to converse and build new friendships. A group of us went to lunch in Tower City and after lunch we had coupons for a free gift compliments of Tower City. We had a choice of a fanny pack or an umbrella. At 2:30 I had an appointment for a free massage. Julie Spiegel of the

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Spiegel Foundation made it possible for burn survivors to get free massages given by professionals. Hat’s off to Julie and her Foundation. At first I was a little hesitant about getting a massage from someone of the opposite sex, especially when he lived right around the corner from me, but what the heck, I went for it. It’s funny but all the guys waiting for their massages were saying, I hope a female gives me mine.

After my massage it was time for me to start saying my goodbyes as this would take several hours, had to find everyone. For me the World Burn Congress ended with numerous hugs, promises to keep in touch and a feeling of richness acquired from meeting the best people in the world.

Your Eyes

By: Michael Appleman

To see the light
Enjoy the day and night

The happiness each day
Yes on the earth we all did stay

Tomorrow will come
Will recovery ever be done

One day we will all see
How true beauty is to be

Everything is in your eyes
Lets reach out and touch the skies

**HOW OUR ATTITUDES AFFECT
COPING WITH ILLNESS**

By: Dr. Debra Moore

Illness is one of the most frightening parts of life. It's not easy to stay calm when faced with prolonged or life-threatening sickness or surgery. But how we react is crucial. It affects both our emotional and physical state.

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When we face what feels like too much trauma at once, we risk leaping straight into the waters of one of the most treacherous rivers of the world ó DENIAL! We tell ourselves something really isn't that important. Or that it isn't even happening. We ignore warning signs of illness. Doctor's visits are put off. We tell ourselves our symptoms will pass. If our fears are confirmed and we are told we have a serious illness or need surgery we may tune out the doctor and remember little of what was said to us. We don't ask questions because we don't want the answers.

Acceptance doesn't always come easily. We try to hide the truth from ourselves and others. But tremendous stress is created when we hide things from those who care about us. It's important that we don't downplay what our condition involves or what we may expect in the future. When others ask how we are feeling, we have the right to tell them truthfully, not pretending what we don't really feel.

Denial, isolation, anger, bargaining, and depression. Common reactions to sickness. There's no "right" way to react, but many researchers talk about these as typical stages before acceptance is reached. You may not experience each and every one. Also, the length of time spent in each stage varies widely from one person to another. You also may go from one stage to another and then back again, especially as you experience new challenges or difficulties.

We all have deeply ingrained attitudes about our bodies and our health. We may go through life without much real awareness of these attitudes until faced with a threat to our health. Many people experience a wake-up call following a brush with death and begin to exhibit a new attitude towards their bodies and their life in general. Our attitudes show up in our diets, our personal self-care, our habits such as smoking or drinking, and our attention to preventative health care.

Most likely, it is as though our personality is under a microscope when we are ill. If we tend to blame ourselves and take on undue guilt and shame, we will

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surely experience this when seriously ill. If we ruminate and worry as a matter of course, certainly we will risk getting stuck obsessing about our health.

Taking action can be our most empowering reaction to illness. This can involve many things, including taking action to educate ourselves about our illness and sharing our reactions with others. Knowing when we need professional help is imperative. Sometimes joining a group of people experiencing the same or similar illnesses can be especially supportive. This can help lower our anxiety, increase our awareness and give us the benefit of learning from others experiences.

Sometimes reaching out to others can reduce the stress caused by brooding. We can feel stronger and more in control when focusing on others. For some, helping others with similar situations is a satisfying way to reach out.

We wish we could control our lives. We like being in the driver's seat. Illness swiftly grabs this illusion away. We can't change this fact. But we can recognize our reactions and realize we have choices in our attitudes. And those reactions and attitudes may even affect our prognosis.

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 or 800-503-8058. If we are not in the office or it is after hours, leave a message in the emergency mailbox. 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.

BSTTW Directors

Michael Appleman: **Executive Director**
michael@burnsurvivorsttw.org

Nguyễn Thi Diêu Trân: **Director- Việt Nam**
tran@burnsurvivorsttw.org

DONATIONS

As a 501 (c)(3) Non Profit Organization, all donations, big or small are tax deductible to the extent of the law. **BSTTW** accepts donations for our general fund, the “Dwight Lunkley Racing To Victory” fund, 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. 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 #305
 Sarasota, Florida 34232

To Donate on line go to:

www.burnsurvivorsttw.org/donations.html

If you have any questions call us at 941-364-8457, 800-503-8059 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. Go to
www.burnsurvivorsttw.org/volunteer.html in order to learn more about volunteering with **BSTTW**. Feel

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free to contact **BSTTW** by telephone at 941-364-8457 or 800-503-8058 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 telephone at 800-503-8058.

BSTTW ADDRESS & PHONE NUMBERS:

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

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