# **BSTTW TEEN NEWS**

Volume 4 Issue 1 January 2004

# **BSTTW OPENING DOORS**

# Burn Survivor Band Records The **BSTTW Songs**

By: Michael Appleman, CEO

After a burn injury, the burn survivors life and their family members lives change forever. The road to recovery for all involved can be very long, hard and painful. With the help of family members, burn unit staff, rehabilitation specialists, **BSTTW** and the burn survivor community a burn survivor and family members can recover and reach goals that will give the burn survivor a new and happy life.

Burn Survivors Throughout The World, Inc. (BSTTW) was started by me, Michael Appleman during my recovery from a burn injury. In May 1998, I was burned due to a cigarette fire in a car. I use to be a cigarette smoker. One night I

stopped to take a nap in the car and I needed my usual cigarette before I went to sleep. The cigarette appeared to be out. I put it in the ash tray without any thoughts of a fire, and went to sleep. A short time later, I woke up to a major car fire. The fire was spreading around the car and my legs were in flames. I left the car and then reentered it in order to

get a bottle of water that I had between the seats. My face, neck and hand was burned from the heat and flames as I reentered the car. My legs were badly burned. I was able to put the fire out on my legs, but the heat spread to my feet, knees and thighs. I suffered 1st, 2nd, 3rd and 4th degree burns.





I was still able to walk at that time. I walked away from the car and sat on the ground. I looked up at the sky and I prayed to God and thanked him for allowing me to get out of the fire. As I prayed the

fire inside the car, got out of control, and the car windows exploded. Again I thanked God. I asked God what he wanted from me since I was badly burned. The only answer I received at that time, was a man driving into the parking lot and coming to my rescue. He told me that saw the fire, went to the local restaurant, called 911 and then came to the parking lot to help me. I thanked him for coming. He and another man helped me get up and walk over to his truck. The fire fighters and paramedics arrived. By that time I was feeling very ill. The fire, heat and chemicals spread around my body. My feet had 2nd degree burns and the shoes were not burned. That is the cause of the heat A FAMILY AROUND THE WORLD that spread around the body. I could not stand or walk. The paramedics did what they could and took me to

the hospital.

Like many burn survivors, I went through a rough recovery. I was in and out of the hospital. I lived in nursing homes for 8 months. Two of my ankle bones were badly burned. Both of my legs were badly **CONTINUED Page 2 "SONGS** 

# Inside This Issue

**Returning To India** 1 **How Safe Is Our Clothing? New Years Resolutions- Making Them Last** 3 **Holiday Life** 

2 BSTTW TEEN NEWS

# **CONTINUED From Page 1 "SONGS"**

burned and my right knee was in 30% contracture. I had plastic surgery, suffered from emotional issues, strokes and heart attacks. I was wheelchair bound and needed someone to help me transfer in and out of the bed, seat and/or wheelchair. Due to the fire, heart attacks and strokes, I was not able to push myself around. I felt that my life was a mess. Emotionally I suffered from post traumatic stress disorder, anxiety and depression. I had to learn how to get myself into the wheelchair and to put my clothes on. This was not what I thought my life was going to be like.



My recovery, like so many other burn survivors, took a long time and was not easy. There was so much that I had to learn, work on and work through. For eight months, I needed help to get into the shower, get dressed, go to the dining room, get in and out of the wheelchair, to get around with the wheelchair, or get outside to smoke a cigarette. I reached out to God in order to find the strength needed to continue this fight and rough road to recovery. During my recovery Marty, a friend, gave me her father's special graduation cross. Marty's Dad was a Catholic Father. I put the cross on my chest and did not take it off. The day before I went back to the hospital for plastic surgery, Marty's Mother asked me to give her the cross back. She then gave me the external cross that her husband would wear when he lead the Mass at church. Both gave me the strength and positive belief during each and every day when even when I was down and out. I always kept the external cross attached to my bed in both the hospital and nursing home. At one point I put it on the wall. I informed all the patients that they can come into my room and pray to God any time they wanted to. Most of the nurses told me that someone was going to steal the cross from me and I should put it away. I told them that it was God's and no one

will take it way. Today I have that cross on the wall in my bedroom.

After 8 months of being in hospitals and nursing homes, I decided to leave the nursing home and return to the people that can help me. I was not getting the rehabilitation needed to push the wheelchair and hopefully walk again. I contacted Marty and asked her to please come and take me to her home. The doctor did not want to release me so I signed all the papers and was allowed to leave. Marty and I went to Church of the Holy Spirit and took part in the healing weekend. After the healing weekend was over, the church staff told me to stay at the healing hotel the church owned and we will work together to find me a place to live. The church made several telephone calls. Within 24 hours after I started staying at the church, I was given an electric wheelchair. The electric wheelchair gave me the freedom I lost since the burn injury. I was able to drive my self around without the help of others. I learned how to transfer from the wheelchair to my bed, toilet, shower and any other place I needed to sit. My life was starting to change. The first night that I had the electric wheelchair, I drove to the outside of the church. I looked at the cross and prayed to God. I thanked God for all the changes in my life and I know that God would show me the way to a happier and healthier life. A short time later the church found an apartment that was available. They talked to the manager and she stated I should come over for an interview. The interview went well, the apartment looked nice and was disabled ready. I signed the lease and had my own home. Soon I would be living on my own and taking another step towards recovery. It was a very beautiful feeling to have your life moving forward after a burn injury. Three days after I moved in, I was in the wheelchair waiting to go across the street. A car hit another car twice and the car came up the sidewalk and hit me. I woke up with many people around me. One of the women reached over to the wheelchair, took my bag and rosary and gave them to me. I help the rosary to my chest and relaxed. From that point on my recovery was more positive.

Within one week, after moving into my own apartment, I found several doctors and rehabilitation specialists that were very interested in helping me **CONTINUED Page 3 "SONGS**"

#### **CONTINUED From Page 2 "SONGS"**

recover from the burn injury and car accident. I began going to rehabilitation 3 times a week. Slowly I was able to do more. My left side, that was working well due to the strokes, began to return. I was living on my own and even cooking my own meals.

During the summer of 1999, I was lucky enough to attend the World Burn Congress for the first time. That was such a very special time in my life. I finally met other burn survivors. Some recovered and some were still in recovery. There was a very special individual that I met during that WBC. He was a male burn survivor who had 3rd and 4th degree burns. Since I was still unable to use my left side at the time, he came over to me and asked if I needed any help getting my breakfast. I thanked him and said yes I could use your help. He helped me get all the food I wanted and then brought it to the table for me. I looked at his hands and saw that he lost most of his fingers in the fire. Seeing how far he has come gave me extra strength to move forward.

I returned home from the WBC and made many telephone calls in order to get the help I needed to recover from the burn injury. I knew if he was able to reach his goals and recover, I and so many others burn survivors could do the same. I knew that I was still missing something in my life. I wanted to walk again or at least have a chance to try. I prayed to God and asked for help. I told God that if I was given the chance to walk again and I was not able to walk, I would accept that and I would accept being in a wheelchair for life. I also asked God to show me what I was to do with my new life. Months later, I was given special leg braces and a walker. After 5 months of therapy I took my first steps. At that point I was given a computer and went on the internet. I researched a lot and then decided to start an internet support group for burn survivors. Using my Masters Degree in Counseling Psychology, I started helping others in need. In 2001, I attended the WBC for the third time and was able to walk short distances. I spoke to many individuals and companies at the WBC 2001. I was able to get the help from other burn survivors and family members, in order to get **BSTTW** incorporated and have a board of directors in order to be given the 501 (c)(3) Non Profit Organization status. With a lot of hard work by me and many others, **BSTTW** has grown to become one

of the top internet sites and an organization that is currently working in 12 different countries around the world.

During 2001, I met Lita Duckworth a burn survivor on the BSTTW internet site. Lita was going through rough times and need support. She reached out to BSTTW and we offered her the help needed. We spoke many times by telephone, emails and the BSTTW chat. She learned how to dust herself off after becoming a burn survivor. Lita worked at dealing with the awful changes that would not go away. She wrote several articles and a poem. The poem was a way for Lita to express the pain and suffering she and so many other burn survivors go through after the burn injury and the help BSTTW offers to the burn survivor community. BSTTW put the poem on the internet for all to see. That poem has been read by hundreds of people world wide.

Over a year ago I began to communicate by email with Ariel Gonzalez. Ariel is a burn survivor, guitar player and founder of Espacio Cuattro. He lives in Saltillo, Coahuila Mexico, Before Ariel was burned he was a member of a local musical band. Then without any warning, Ariel suffered severe burns to his in the hand, arm, chest and face in a home fire. At the time of the accident, Ariel was Catholic, married, had three children and a loving family. He enjoyed writing songs and playing the guitar for a well known band in Mexico. Ariel suffered 2nd and 3rd degree burns to his hands, arms, face and chest. After the fire Ariel did not want to give up hope that he will write music, be in a band and continue playing the lead guitar. Playing the guitar again was not an easy goal to reach. Ariel suffered third degree burns, nerve damage to his left and right arm and hands. He had several surgeries to those areas and wore Jobst Hose for an extended period of time.

The emotional and physical pain that Ariel suffered due to the burn injury was not easy to deal with. Ariel, like many other burn survivors, continually reach out to the most important individual in his life...God. He prays daily asking God to allow him to recover and live a happy and normal life. In time, with his family and friends by his side and after many surgeries and extensive rehabilitation, Ariel was able to reach his goals. Every time Ariel spoke to the band members or looked at his guitar, he CONTINUED Page 4 "SONGS"

# **CONTINUED From Page 3 "SONGS"**

reached deeper inside to find what was needed to rebuild his life. Part of Ariel's rehabilitation was to exercise the hands by playing the cords on his guitar. After a lot of hard work, Ariel was able to restart his musical work. He rejoined the band and began to show all that the burn did not end his life. Today each and every time Ariel plays the guitar he still suffers a lot of pain in his hands. Both hands still have staples inside of them. That pain and suffering did not stop Ariel from moving forward with his life.

Six months ago, after being in contact with Ariel for over one year, I decided to email Ariel and find out if he and his band would be interested in writing the music and recording songs for several BSTTW poems. Ariel read the poems and said that he would like to take part in writing the music and recording the songs. Ariel stated that his band and other musicians in Mexico would like to take part in writing the music and recording the song. The musicians knew that Ariel was a burn survivor and that the song would be the music used by **BSTTW** on the internet, in conferences, radio stations and public events. Ariel and the musicians let me know that they would like to record the song in both English and Spanish. I thought that would was a fantastic idea. After working on the song for several months the musicians got together and recorded the song. They were very happy with the results. On Thursday October 30, 2003 the CD arrived at the BSTTW office. It was a fantastic feeling to open up the CD and listen to the music. Ariel and his band did a fantastic job. The love was flowing from the musicians and singers. You can feel that each individual involved in the making of the song and the CD, took a very special part in helping Ariel, **BSTTW** and the burn survivor community. **BSTTW** world like to thank Ariel, his band, the recording company and all others involved for all the work they did. Ariel Gonzalez is an example of a burn survivor that did not allow the burn injury to stop him from reaching his goals and doing the best he can after the accident.

Ariel like so many other burn survivors, learned a lot about life due to the burn injury. He found more strength in God, love for life and the ability to never give up when the chips are down. Today Ariel is the BSTTW Representative in Mexico and has started to speak with doctors and nurses in the burn unit about

the work he and BSTTW offers to the burn survivor community and the public. Ariel has also spoken with burn survivors and family members explaining his injury, God's love and strength and his road to recovery. Ariel has helped many burn survivors and the public to understand that a burn injury does not end your life. Ariel is currently opening up doors for our current and future burn survivors in Mexico, the USA and other parts of the world.

The BSTTW board of directors, Ariel and his team felt that the song would help other burn survivors, by speaking the love for life, expressing the changes due to a burn injury, opening up doors for **BSTTW**, and helping the public to become more aware of what a burn injury can do to a human being from the day of the accident and their future. I personally felt that I was again reaching another goal for **BSTTW** and in my life. Again I was opening up many more possibilities for **BSTTW**. The words from this song can touch the hearts of many. It may also help our current and future burn survivors and family members to understand that life has changed, but it is not over. They will see that two burn survivors had an important part in the song. During the practice and recording sessions for the BSTTW songs, Ariel reached deep inside and found the strength he needed to make the BSTTW songs the best they can be. Ariel is a burn survivor who we all can learn from. Ariel Gonzalez never gave up during his recovery and reached goals that many individuals in the burn survivor community and the public thought could never be accomplished.

BSTTW is selling the CD for \$10.00 plus shipping and handling. You can learn more about purchasing the CD, read the words to the songs and hear the music at www.burnsurvivorsttw.org/articles/bsttwsong.html

# Returning To India

By: Shirin Juwaley

Life in US as a burn survivour posed no problems for an Indian like me. People in US were extremely kind and more acceptable. There was no need for me to hide my face behind a veil and I could simply walk like any 'normal' person. Yes, I was stared at many times when I went to public places. That is expected for a burn survivour. Life was indeed simpler here than in India, or was it???

Actually... No! Life is simple where ever you go. The difficulties I encountered, including the social rejection that I faced in India, was my own rejection of my body and face. The mere thought that life will be simpler in USA was only in my mind. Life being easier in the USA, or I felt that I was more accepted in the USA, was only because I had accepted myself as a burn survivor, along with my permanent scars and disfigurement! I returned to India with a lot of fear. As time went by I realized that after working through my issues that my life in India was not as bad as I feared.

It has been a year for me since I came from USA. I'm settled in Mumbai - the heart of India. Life is ever so beautiful and as easy as it was during the time I lived in the USA. Today I go out without a veil and enjoy the freedom that my body, mind and soul has given me. People are forced to accept and commend my courage to Live Life King-size!!!! I suppose my demeanor demands other to "Look at me, I'm a human being too, just like you, I feel, I hurt and I cry, just like you, so please do not ignore me because it has taken me tremendous amount of courage & time to be able to rub shoulders amongst you."

Believe me friends it's all in the mind. Today I have a lovely job and I work with marginalized children trying to make a small difference in their lives. I thank God for blessing me with a life of a burn survivor. Remember that it takes time and hard work, but if you do what I have done, you will be able to reach your goals, find true friends and rebuild your mind, body and soul.

# How Safe Is Our Clothing? By Delores Gempel Lekowski

A beautiful little four year-old girl was proudly wearing a dress that her mother had just finished sewing, having put the finishing touches on it that same morning. The little girl had helped her mother pick out the dark blue material with purple and white flowers, and she was excited to show off the new dress that her mother had so lovingly made for her. The dress was a jumper, and the little girl wore a turtleneck shirt under it. She was dressed to go out to dinner and could hardly wait to show off her lovely new dress. While her mother was out of the room, the little girl climbed up on a brick wood-box so she could turn on a light near the mantel. A candle was burning on the wood-box and, as she reached over it to turn on the light, her dress caught fire. The little girl started screaming and running for help, but by the time she reached her mother, she was already completely engulfed in flames. She suffered third degree burns on 90 percent of her body, and only a small piece of the dress and the collar of the turtleneck remained.

I will make the assumption that the majority of the population doesn't consider fire safety when they purchase clothing or fabric. We as consumers have a false sense of security, because we automatically assume that what we buy is safe. In fact, there is a minimum flammability standard that must be met by all general wearing apparel and fabric sold in the United States. However, that standard is 50 years old and grossly inadequate.

The Standard for the Flammability of Clothing Textiles (16 CFR 1610), which is enforced by the US Consumer Product Safety Commission (CPSC), first emerged as the "Flammability of Clothing Textiles, Commercial Standard" in 1953 as a specification of the Flammable Fabrics Act (Pub. L. 83-88, 67 Stat. 111). While standards for children's sleepwear have been made somewhat stricter, the general wearing apparel standard has been largely ignored. This is not because the standard serves safety; in fact when you consider that newspaper and tissue paper will pass, you have to wonder how effective this standard really is. Obviously, it wasn't strict enough to prevent this four year-old little girl CONTINUED Page 6 "CLOTHING"

### **CONTINUED From Page 5 "CLOTHING"**

from being burned, nor has it prevented countless others from being burned similarly.

In 1951, even before this minimum standard went into effect, the dress I was wearing went up like a torch in seconds when ignited by a spark from a pile of burning trash. I'd like to think that the fabric from which my dress was made couldn't be sold today. However, I have discovered that there are still fabrics on the market that have the same instantaneous flashpoint as the fabric of the dress I was wearing that fateful day. And every day, the very old and the very young, in particular, are in danger of becoming human torches if they are unlucky enough to encounter an ignition source.

Even the sleepwear standard has been relaxed. In 1996, the CPSC decided to amend the flammability standards for close-fitting cotton sleepwear for kids. Also, when you think about the children's sleepwear standard, many kids wear t-shirts to bed. T-shirts are not covered under the sleepwear standard, so effectively children are right back where they started, in many cases - unprotected.

When I think about the advancements we have made in other areas of safety and technology over the last 50 years, I find the lack of concern or progress in promoting the safety of clothing fabrics to be a disgrace. Certainly, the textile industry was instrumental in making sure that the standard resulted in the most minimal requirements on their part, and in the past half-century, the industry has done everything possible to prevent the standard from being changed. The CPSC is currently looking at "updating" the general wearing apparel standard (an advance notice of proposed rule was issued in 2002), but the proposed changes are minimal and do not make the standard more rigorous. Individuals and organizations, such as the National Association of State Fire Marshals (NASFM), have enjoined the CPSC to take a strong stand for the safety of the consumers it represents and make some decisive changes to improve the standard. It remains to be seen whether this will happen.

However, a new project involving the CPSC, the American Burn Association, the Shriners Hospital for Children and NASFM gives reason for hope. The National Burn Center Reporting Project will collect data in order to develop a more accurate picture of burns involving children aged 15 and under. The CPSC will work with emergency responders and burn hospitals to retrieve and analyze the clothing worn by burned children to determine what role the fabric may have played in the incidence and severity of the burn injury and to develop a more informed judgment about how the ignition could have been reduced or prevented. This is an important step in the right direction - but I, for one, won't rest until that 50 year-old wearing apparel standard is strengthened.

In the meantime, we all should take the time to remind clothing manufacturers and retailers of their moral obligation to keep hazardous products out of the marketplace. Adherence to a minimum standard is no protection against liability, and should never be an excuse to make or sell products that could turn any of us - but particularly the most vulnerable among us, our children and elderly - into human torches.

# New Years Resolutions - Making Them Last

By: Dr. Debra Moore

Making them is easy - keeping them is hard. It's estimated that only 20% of people keep their New Year's Resolutions, and that on average it takes five long years of promising ourselves to make a change before we actually put it into action.

Therapists know there's much more to making changes last than simple intention. If that were the case, no one would need our assistance –they'd just do it.

There are predicable stages in making changes. First we have to break out of our denial. We have to face facts- whether it's admitting that smoking is dangerous to our health, that we are spending more than we can afford, that we have become inconsiderate of others, or that we have gained way too much weight. Only then will we start contemplating change. At first, we only flirt with the idea. Later we find ourselves thinking about it more frequently. At some point, a commitment is felt deep inside and we move into action. Later stages include **CONTINUED Page 6 "RESOLUTIONS"** 

#### **BSTTW TEEN NEWS**

#### **CONTINUED From Page 5 "RESOLUTIONS"**

maintenance and recovering from lapses.

As we contemplate making resolutions for change, several steps can be helpful:

- 1. Take an up close, honest look at the real reasons you haven't changed before. You may have some preliminary work to do before you can successfully make a change. For example, if you are overeating out of unresolved grief over your divorce, it's not likely that you will lose weight until you have worked through these feelings. If you're stuck in old unfinished business, seek out some counseling and begin moving past it.
- 2. Define some small, specific steps that will move you in the direction you want to go. It's one thing to say you want to exercise and quite another to figure out the when, where and how's of your exercise plan.
- 3. Take ownership of your changes. These are your goals, not your spouses, your parents, or your bosses. It's estimated that goals set mainly for the benefit of others on average last only six weeks.
- 4. Consider making two goals at once. There is some evidence that one reinforces the other, instead of making it more difficult.
- 5. Build in support. This can mean telling others who will encourage you, or actually joining a support group.
- 6. Realize that the world is not black or white, all or nothing. Most journeys include a few wrong turns or delays. Interpret lapses as signals, not failures.
- 7. Track your progress so you can see the results. Plan to reward yourself along the way.

# Holiday Life

By: Michael Appleman

Holiday life what will it be? Enjoyment is that what I will see?

Since the accident all I know The pain and suffering will not go

Sharing it all is what I would like Will I travel on the bike?

The Christmas tree is so far away Will I go home to see it today?

Enjoy and share what you have each and every day Remember soon it might all be taken away

### Michael Appleman

**BSTTW** is always looking for new poems and stories. Expressing your life, love, recovery, and emotions helps you and others move forward in the recovery process. You can submit a poem or story on line by going to:

#### Poems:

http://www.burnsurvivorsttw.org/poems/poemmaker.html

#### Stories:

http://www.burnsurvivorsttw.org/stories/storymaker.html

# 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

Ariel Gonzalez: Director- Mexico ariel@burnsurvivorsttw.org

Nguyên Thi Diêu Trân: Director- Viêt 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 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