BSTTW COMMUNITY NEWS

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BSTTW REBUILDING LIVES

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.



A FAMILY AROUND THE

Remembering back to the days, weeks and months during our recovery, when each second of the day felt like they 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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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 your get the funds needed to attend the WBC 2004 you can contact BSTTW at wbc@burnsurvivorsttw.org or at 800-503-8058.

Corrective Pigment Camouflage Part 1

By: Susan Church CCPC

This is part 1 in a 3 part series. Part 1 will deal with the consultation of a burn patient. This will include: patient expectations, the ability to tolerate pain (preprocedure sedation), consulting with the patient's physician, pre and post care and photos.

Our primary concern is to correct tissue color defects and create the illusion of smoother looking skin.

Dr. Francis Cook MacGregor, a research scientist and member of the rehabilitation team at New York University Medical Center states "In our culture the way one looks makes a difference in the response one gets. It is this fact that defines one's identity because it defines the reaction of others." The mouth is the second most noticed feature of the face, preceded only by the eyes. The disfigured face may be transformed by plastic /reconstructive surgery, corrective cosmetics or by Corrective

Pigment Camouflage (CPC).

Patient assessment includes two phases: collection and analysis of information. This is achieved through the interview and examination. Most burn patients have lower self-esteem, social anxiety and fear of rejection. With this in mind, it is imperative to obtain information vital to your overall plan. The patient's past and present medical records contain data helpful to your overall assessment. These records should include a complete medical history including allergies to food, anesthesia, drugs, chemicals, metals, etc., and any diseases or disorders (psychological or physical).

Technicians must establish a rapport with the patient, identify their needs and agree on goals. We thoroughly discuss their perception of their present situation and what the CPC can do. Patients must be made aware this procedure is a multi-step process and final results cannot be determined until all applications are completed.

When a person initially phones for a consultation, the technician must ask whom the patient's physician is and if they are presently under their care. If they take medication or plan surgery in the next few months, the technician must work in concert with their physician.

The evaluation should include the use of glycolic or other Alpha Hydroxy Acid (AHA) prior to procedure day. This exfoliation/desquamation is the process of **CONTINUED Page 3 "PIGMENT"**

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removing dead cells from the epidermis.

This application will remove only dead, not living tissue. The technician should ask the treating physician if the patient should see a dermatologist to set up a skin treatment program. The cell renewal rate is generally every 21-28 days. For younger individuals, it is 3-4 weeks, for middle age adults it is 4-7 weeks and a mature adult's skin regenerates itself at a rate of 7-12 weeks or longer. This information is also vital when rescheduling the patient for their next appointment. The exfoliation process makes the skin more receptive to pigment retention.

The technician will discuss what is feasible for the patient to achieve with CPC, showing photos of other burn and scar work from onset to finish. Even though every case is different, this will enable the patient to see what is possible to achieve. The technician should write a detailed description of their treatment plan and go over it with the patient. Both of you must be in total agreement will all phases of CPC. Getting involved in their treatment should help give the patient control over their life, get them excited, and give them confidence.

Photos will be crucial in developing your overall plan of assessment for CPC. We photograph the patient's areas of concern and mark the areas. Patch color tests in marked areas of the skin will allow the technician to determine future colors to be used during application. An examination of facial morphology and symmetry is crucial.

We always have visible proof of our work as documentation for any and all interested parties, which may include physicians, worker's compensation cases, and insurance companies. attorneys, technicians and others.

Most patients have been through numerous surgeries and they are either oblivious to pain during procedures or the pain is very intense. We use a topical anesthesia to reduce the pain. We have found the best anesthesia to be ULTRAcaine White by Tri-Lab Products and/or Ela-Max 5, applied and wrapped in an occlusive dressing. Anesthesia is

applied 1/2-1 1/2 hours prior to procedure application. We also use 1-2 drops of Numit liquid anesthesia in our pigment.

Below are before and after pictures of corrective pigment camouflage on burn chest scars. These pictures show the changes this procedure makes.





Pre-care includes - Patients should drink 8-10 glasses of water daily, as this hydrates the skin. Other considerations include: limiting intake of caffeine, sodium, aspirin and alcohol 3-5 days prior to each procedure.

Susan Church CCPC
Director of Education International Institute of
Permanent Cosmetics
Director of Clinical Research and Development

For product information on ULTRAcaine White, NUMIT LIQUID and Ela-Max 5, telephone number: *Tri-Lab Products* 714.839.6543 or email Susan Church at susanchurchcepe@yahoo.com

Protein Power! Build Your Body Back to Health Cell by Cell By Paula K. Burke, RD, LD

Here's hoping that this newsletter finds all in good spirits and better health. This time I would like to talk about why protein is so important in burn recovery. The first article gave some information on what makes up a nutrition assessment. The main point to walk away with is that the burn patient needs *MORE. More Calories! More Fluids!* and *MORE PROTEIN*.

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CONTINUED From Page 3 "PROTEIN" WHAT is Protein?

Proteins are the *structural units* of all cells in the body. This includes muscle, bones, and all body organs, including the skin. In addition to providing structure, proteins also perform many *actions* within the body, for instance, <u>enzymes</u> that are used to digest food are proteins. Body metabolism cannot occur without enzymes. <u>Hormones</u> are also made up of proteins. Hormones regulate body processes such as sexual function, growth and development, and the sleep cycle. Proteins are also very important in the immune system. <u>Antibodies</u> that fight infection are actually proteins too!

All proteins are made up of strings of individual amino acids. What makes one protein different from another is just the order in which the individual amino acids occur in the string. Most of us have heard the terms 'non-essential amino acids' and 'essential amino acids'. The strings of amino acids that make up a protein contain both non-essential as well as essential amino acids. The difference is this: while the body can break down it's own protein (such as muscle) to provide non-essential amino acids that make up whatever protein the body is building, essential amino acids must come from outside the body in the food we eat. If this does not happen, the protein will not be completed. Think of it like as assembly line where the body is happily humming along stringing Cysteine to Glycine to Proline to Serine to??? "Hey where's Arginine??" Until Arginine comes along, the assembly is SHUTDOWN.

The body is a dynamic being, which means that proteins are constantly being broken down and built up again. That is why it is so important to not only eat enough protein, but to make sure that enough of both essential and non-essential amino acids are in the protein foods we eat to make sure the body can, you guessed it ... function optimally.

How Much is Enough?

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In burn patients, there must be enough protein to provide for basic body structure and functions plus extra protein to promote early wound healing and support the immune system. Later on extra protein helps to maintain skin tissue strength to support successful skin grafts or reconstructive surgery. In children this can be up to 2-3 times the normal Recommended Daily Intake (RDI) of protein for age. For most adolescents and adults this can be up to 2-3 grams of protein per kilogram of body weight per day.

Which Foods Contain Protein?

Eggs, Meat, Poultry, Fish, Beans and Legumes, Soy, Cheese, Milk, and Yogurt are all very good sources of protein. Eggs are considered the 'gold standard' of protein because they contain all of the essential amino acids in the optimal amount. Protein that comes from animals contains all of the essential amino acids whereas proteins that come from beans, legumes and soy may not. Other foods that contain protein in far lesser amounts include rice and other grains as well as vegetables. Many proteins that come from beans, legumes and vegetables are more 'heart healthy' than the proteins from animals however, and so it is still very possible to be a vegetarian and still get the full amount of essential amino acids. It just takes a little more thought when it comes to planning your meals. Vegetarians should know that in order the get 100% of their essential amino acid requirements they need to eat 'complementary proteins' together. An example of two complementary proteins that together make up a 'whole' protein is beans and rice.

Now a Tasty and Fun Example!

Here is a good smoothie to try:

Mix in a blender:

1 6-8 ounce container Regular Yogurt (*Not* Low Fat or Low Carbohydrate)

1/2 cup Whole Milk OR Calcium Fortified Soy Milk 1/2 whole banana OR 1/2 cup other Fruit CONTINUED Page 5 "PROTEIN"

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1/2 cup Ice Cream
2 Tablespoons Chocolate <u>OR</u> Caramel Syrup
Blend to desired consistency. Top with 1
Tablespoon Granola **or** Wheat Germ

This can provide up to 600 calories and up to 16 grams of protein.

It is also possible to prepare shakes and smoothies with many oral supplements that are readily available in many grocery and drug stores. Many of these supplements are also lactose free and contain additional vitamins and minerals as well. These supplements include Ensure®, Sustacal®, Resource®, Boost and Carnation Instant Breakfast®.

That's all for now, until next time **BE POWERFUL and WELL!**

The WBC and Me!

By: Delores Lekowski

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

What you will walk away with will far exceed you 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 vesterday 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 grieve, 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 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) aet 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 **CONTINUED Page 6 "ME"**

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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 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.

The Burn Recovery Part 1

By: Dan Tetrick

When I was asked to write this for BSTTW, I have to admit that I balked at the idea. I had decided a few months ago that I wanted more than anything to use my spare time to help other survivors and their families cope with the most devastating of injuries. It took a lot of persuading for me to sit down and start writing this. Maybe this will help you or your family in a way that my singular perspective can't see. There are so many things in life that are miraculous, one of which is the fact that we can learn from one another without experiencing exactly what they have.

It's strange the things that run through one's mind when he/she believes that death is inevitable. The world, which is usually a million shades of gray, simplifies and becomes black and white. Questions are clear cut; and answers are too blunt even for the coldest of hearts.

Believe it or not sitting here in front of this computer...I can remember every thought that ran through my head. Sometimes, the thoughts haunt me to sleep even now, 15 months later. I can still feel the same fear, guilt, torment, and yes even happiness that those thoughts gave me. I wonder if I am the only one. Even though I know that it must be impossible, I still feel alone battling this.

This story isn't about those few minutes on the edge of oblivion; this story is about all these months coming back. Sure anyone can dance with the Devil and become a victim, but not too many can become a survivor. A survivor being a state of mind, not an action, a place in your heart where you are always fighting for more despite the obstacles. This is my journey, and I hope daily that no one will ever have to go through the same thing.

"I'm going to die." There was no fear in this thought as the house burned all around me. The realization of the inevitability of death was academic, **CONTINUED Page 7 "RECOVERY"**

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with the tone of how we all used to say, "This sucks."

I lay on the floor of my bedroom, flames ripping through the wall, smoke racing against the oxygen for the finish line of my lungs. I lay there with the charred remainder of my skin sticking to the carpet in a puddle of my own fluids thinking that the whole situation sucked like none other. I knew that there was no hope, no miracles, no Santa Claus, just death, and probably a nice vacation in Hell for the likes of me.

What had I awakened to? Hell.

It was a Thursday night, but they had a three-day weekend ahead of them so to stay out past 2 getting trashed was the only sensible thing they would do. My step-father, Terry, was by this time a hardcore alcoholic. I remembered fondly the times when he used to get drunk every other day with a "hang-over" day in the middle. It was like clock-work. He'd get drunk on Sundays be sober on Mondays and Tuesdays, and then really get into the every other day swing of things by Wednesday night.

Those days were long gone by December of 2001. Terry was drinking every night. He would walk in the front door without saying a word to anyone in the house... and then the noises and singing would come from the kitchen. The opening of the refrigerator followed by the creaking, nonlubricated hinges of the cupboard. The cracking of ice and the almost beautiful sound of ice cubes landing in a glass. The gurgling joy springing from the bottles of Kahluha and Vodka mixed with the humming of a man readying himself for a treat he'd been thinking of all day in the hot sun. Finally, the one "kerplunk" from the gallon of milk...and the clinking and sloughing of the concoction as he shook it gently in circles. Then the announcement; which was something different everyday, but the most common being, "THE RUSSIANS ARE INVADING!!!!"

Terry was a good guy for usually two White Russians. These were actually the times where we

got along the best. He was tipsy enough to be humorous...and believe me he could be a riot...but not yet drunk enough to get loud and mean. I would retire to my room as soon as I heard the third White Russian being made, and hope that he would by some miracle leave me alone for the night. The alcoholism had really been showing in his behavior for the last month. He had lost the edge that made him an "Alpha Male." I could actually see him getting older in front of my eyes. It was as if all the years of drugs and booze had caught up to him. He was getting flaky.

That Thursday night was the same thing as all the previous weeks, but I had plans to leave...so I wasn't too worried about him. I figured my Uncle Sam and him would probably end up at the bar shooting pool and getting wasted to kick off their three-day weekend. I knew that if I timed everything right I could be out the door by Terry's third drink and back home before they got back from the bar. I would miss the drunk completely. This added to my already incredibly good mood.

It was going to be a good night. I was throwing a going away party for my best-friend, Biagi, because he was getting stationed in Germany. I wanted to get all of the friends we had left in town and have them meet us at the local hang out, the pool hall, a hole in the wall with lots of class. Biagi had been home from his Advanced Individual Training (AIT) for about a month, and during that time my old friend had helped me get out of the shell I had put myself in after a major lung surgery that ended my chances of going into the military, and an extremely recent break-up with the girl I planned to marry. I owed him the best damned going away party I could throw. I figured we'd have a good 15-25 people ... and I'd made plans with the owner to save me all the tables at the back of the hall, 5 of them. It was going to be a night we never would forget.

At about 7 pm I took my shower while Terry was one White Russian in and Sam was two beers down. Of course everyone wanted to know what I was up to, so I gave them the low down running **CONTINUED Page 8 "RECOVERY"**

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through it as fast as I could so I could be out the door within the hour. By 7:45 I was looking good, standing tall, smelling sweet, and ready to go and have fun.

As I walked out of my room I got cat called by the family. I was used to this, considering I had been called the "pretty-boy" more times than I can remember. I smiled, winked, and runway model walked to the door with my pool stick case swinging from my shoulder. It was time to have some fun. Not surprising was the fact that Terry had more alcohol while I was getting ready, and had more to say because of it. The gist of it being he didn't approve to me taking my Mom's car and not giving her estimated time of arrival back at headquarters.

Mentally fencing this drunken man was more difficult than it may seem to you my reader...but Terry could be a most cunning animal when provoked. Within 10 minutes he had won the battle. I had given up an ETA of 1 am. As I faced the door Terry called my name. Tensing for the next volley of madness to spew from his lips I turned back to him, and realized he'd gotten up from the couch and was moving towards me. I thought I was about to get my clock cleaned for sure. Instead he gave me a hug and whispered something into my ear, " I love you boy, and I'm just looking' out for ya." he said in that quiet southern drawl. I hugged him back and said, "I know." With all of that said and done I went out the door knowing that I was going to be late to the party I was supposed to be hosting. I had to make up time, and since time was of the essence, I forgot the car keys in the house.

Kicking myself in the butt and knowing full well I was going to get back into another joust with Terry, I ran back into the house grabbed the keys and headed back for the door. Right at the door Terry said 4 words to me that will stick in my head forever as being the most ironic and the most well meaning words I'll ever know.

He said, "Be safe. Be careful." And I looked him right in the eye, and gave him the last warning he would ever hear for the rest of his life...about 7 hours, "You too, old man."

Eight words; for some people 8 words might not seem like a conversation, but those 8 words meant a million different things. We both knew that we were talking about more than just the common dangers, like getting AIDS, or getting drunk and driving home. We were telling each other in our own ways that we were both hard headed, stubborn men that liked and disliked one another, respected and despised each other, but when all was said and done love was at the root of it all. 8 words.

"Be safe. Be careful." "You too, old man."

I got back from my party, which was a blast, around 1:30 am. I wasn't too terribly worried about getting caught coming home late, because my "child of an alcoholic logic", was perfect. They weren't home yet from the bar. I made my way to my room, got undressed, set my alarm clock for 6:30 am and promptly went to bed with a smile on my face.

There is no way of telling when everything started, but having read some statements from witnesses I know that the ball really started rolling around 2:30 am on December 14th, 2001. It would make good sense because my Step-father and my Uncle wouldn't have left the bar until it closed at 2.

My Mom, mostly out of habit, cooked a dinner for no one. She deep fried some shrimp, ate what she wanted, and put the rest away for us to eat when we came home...or as leftovers later in the week. She put the pot of grease on the back burner for it to cool, and went to bed. She still feels this enormous sense of guilt about that grease. I tell her when she is down that if it was hot she was supposed to move it away and wait for it to cool before disposing of it. It doesn't help I know, guilt is a thing that the person experiencing it must release themselves.

When they got home Terry went to bed, but Sam got hungry. I don't know if he ate all of the shrimp and was still hungry, or if he never found it and wanted to make some, either way he moved the **CONTINUED Page 9 "RECOVERY"**

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pot back to the front left burner, turned it on, and passed out.

What awakened me was the heat. I got out of bed thinking that I wasn't going to get enough sleep for work, except there were only expletives running through my head. I turned on my ceiling fan, and pulled my floor fan closer to the bed. With those tasks accomplished I went right back to bed. I couldn't have slept too much longer when the smoke detectors went off. I opened my eyes, thinking that maybe I should call into work so I could take Biagi to the airport and catch a few more hours of sleep, when I heard a man's scream of pain coming from the living room.

Instantly I was up on my feet angry, having registered the fact that it wasn't 6:30 am, and thinking that Terry and Sam were having a fist fight. I hit my door with my full force hoping to get their attention before I started screaming. My voice caught in my throat. I never expected to see what I was looking at. Light and darkness could never mix like this. Smoke everywhere; black smoke. Orange light trying to break free of the shackles of that darkness, fighting against it to reach my eyes. I had come out thinking I was going to unleash hell, what I got instead was hell unleashed. I could only stare feeling the unbelief creep into me. This is impossible. This can't be happening. What IS happening? FIRE!

"FIRE! FIRE! FIRE! EVERYBODY GET THE HELL OUT OF HERE!" I don't know if it was the sound of my voice that made him respond, but Sam ran from the kitchen, a candle burning screaming in such pain that I'll never forget that vision nor the sound of his voice. He came a dozen steps out into the living room stopping to turn back only 5 feet to my left. He spun right back into the kitchen screaming, and then the sound stopped. All sound stopped. The smoke detector had died God alone knew when and I was standing there looking into the kitchen, into the fire and smoke, listening to the fire crackle the pleasant way it does at a camp out. That soothing popping almost like white noise in it's simplicity.

I had seen enough, experienced too much. The panic gripped me and tore my sanity away. All I wanted was out. I turned to my right and ran straight for the door. Even through my panic I registered and remember too much. I looked by the door a few feet away and I could see the water in our fish tank boiling. I have tried to tell myself that this is a hallucination after the fact, but that always feels like a lie. The water boiled. I couldn't see the door knob a few inches away though. I kept fumbling for it, reaching too high, too low, too left, too right. I gave up on the knob and began to throw myself against the door. In my panic stricken mind I thought my 160 lb frame was going to bust that door down. I didn't think that the door was steel reinforced, and some kind of metal in itself. I only threw myself into it harder and harder, not registering any of the heat. Not thinking that I was cooking myself. It was only the shortness of breath that made me leave that

I turned back towards the fire knowing now that I had to run back through it to get air that I could breathe. I had to get back to my room. There was no smoke in there when I first came out. I didn't hesitate; these thoughts were running through my head as I made the sprint through the fire and into my room. I hit the floor and I could breathe again. I grabbed the floor fan that I had turned on earlier and drug it down on the ground next to me. By turning it upwards, it pushed some of the ever thickening smoke away from my face. I lay there with my head on the fan, the cool air blowing into my face, and thought a billion thoughts.

door.

From the ground, I could hear Sam screaming again. Why didn't he just die? He screamed over and over "God FORGIVE me! Terry FORGIVE me!" incessantly. I don't know if he ever stopped. I was terrified. I don't know if I wet myself, the dramatic motion picture portrayal of fear, because I didn't have time to think of that. I didn't have time for anything. The fire moved so fast in that old pine house with pine interior paneling. I thought a million thoughts but none had to do with how I might or might not die in clean underwear. I couldn't feel pain. I couldn't really feel the heat in any way other than an academic sense. All I felt was death CONTINUED Page 10 "RECOVERY"

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Death in the form of a flame moving towards me like a monster out of a book that I might have read as a kid on a rainy day. One of Danny's monsters that kept him from going out and playing on clear days too. There is no other way to describe that fire other than to personify it like it truly had a mind. It wanted me and it spoke to me deep down in my heart. It made me change from a cocky manchild of 18 into a crying kid of 3. This was all too much to take in. I thought that I should go out my window above my computer, but I thought to myself, "Terry would be pissed if I broke a window."

Nothing rational in my mind was totally rational.

I felt every emotion in the spectrum lying there on the floor waiting to die. I felt anger that my life had been so pointless, that I never made up for all my mistakes growing up. I felt embarrassed that I was going to die like this in my own house on my own watch. I felt sadness that I was never going to say I love you again to anyone. Then, I felt release, as I accepted my death. And happiness, that I was loved for a time by people that truly understood me, even if they weren't all in my family. My family! They were going to die too! Wasn't Sam dying?! And as if that was the keystone to my arch of madness I heard my Mother scream that she had the door open.

She had awakened to my screams and the sound of the smoke detectors before they burned up. She reached across the bed and hit Terry as hard as she could to wake him. She told him there was a fire, and Terry being half asleep and totally drunk told her, "I'll take care of it in the morning." She hit him again and told him to get up "NOW!" She moved through the house with a lot less panic than I did. I think that if there is a God he used her as a tool. She moved carefully around the walls of the living room, approaching it from the opposite side that I did, and made her way to the door. Through the smoke she couldn't find the doorknob either, but somehow she laid her wrist against it, giving her the only visible scar she has today on the outside. When she walks in public it isn't noticeable, few people would think to look, even then they would think her lucky till they

saw her back. A 6 inch triangle of graft against her left wrist is the visible price she paid to save two lives. A small price in the scheme of things, but my Mom was Super Woman at that moment...and I'll always owe her my life twice over.

Terry, it seems had not followed her along her path. He went to the bathroom to get his contacts in. He must not have realized that even with good eyesight visibility in that house of darkness and light was impossible. Those few seconds might have been the very thing that cost him his life. There is speculation in my family as to what exactly he did to not get out of that house. I have read the fire reports, and I have eye witness accounts from my Mom that make me think what I think, but it was the Medical Examiner's report that told me he stopped for his contacts, but didn't waste the time to put both of them in. No matter what happened, the last time anyone saw him alive was when my Mom smacked him awake.

There was a pop, like a cork letting go of the glass sides of a bottle when the door opened. I heard my Mom say loudly, but not scream, "The door is open. I've opened the door." Upon hearing those words, I knew that my last chance for redemption was here. It was now or never. Live or die. This was so clear it should have been in neon running through my mind. I HAD TO GO NOW! I could see the fire eating through the wall of my bedroom. I could see only orange outside of my door, but I knew I had to go through it to get to that magical place...OUT.

I picked myself up into a sprinter's position and made my mad dash for OUT. I came out of my room into the fire or the living room I didn't know. I hit my Christmas tree that ignited as I went past. The floor was melting under my feet, but I couldn't see. Then there it was. A rectangle where the smoke was running, there was light out there! Then uneventfully it seems now, I was out and it wasn't that magical after all.

Neighbors were standing in the yard. Looking in awe at the flames which were reported CONTINUED Page 11 "RECOVERY"

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as going 25 feet into the air. They were looking at me looking at something that was covering me. One of them made a move too quickly and I jumped back looking down at myself. I saw my skin hanging from the tips of my fingers to the ground. I saw this, knew what it was, but when I woke up in the hospital some time later I was shocked to find out how bad it all really was. The skin was black and twisted. It looked like plastic that dangled from my body. I think it might have been on fire when I came out, but that story is a mixed one. Some people say I was lit, others just say I looked like death himself. I looked at the man and screamed for him to get away. Leave me alone. I stood for awhile in place screaming "IT BURNS! IT BURNS SO DAME BAD! MAKE IT STOP! OH GOD OH GOD!" Then there is a pause in my story because there is a black spot in my memory. I know I went to my Mom's car and laid upon the dewy moisture that it presented. It sounds sick that months later I discovered this when I had to clean the car, and realized that the black thing on the hood looked like a butterfly, or a back print and I fit perfectly.

The next thing I remember is walking up and down the street asking where my Mom was. Time kept speeding up and slowing down, it's hard to measure even now. What might seem like minutes and seconds to you my reader...can't be measured in my own mind either. I was told that my Mom was at a neighbors. That she was ok. That I should go to. That fire trucks were on the way. A million stupid things that didn't matter. All I wanted was to see if my Mom was alive.

I found her in the dining room of a neighbor's house having her wrist wrapped in ice. Not the smartest thing I have learned, but all they could do for her. No one wanted to touch me and everyone cleared around me so I could get to my Mom. She was black with soot. Her beautiful, if sometimes (she thinks anyway) stringy blonde hair wasn't recognizable. She wasn't recognizable. She was another monster. A monster that only kept repeating. "Where's Terry? Where's Danny?" Nothing was getting through to her. I touched her shoulder and she looked up. Her face was swollen and she was

crying clean tracks through the grit of the soot. "I'm right here Mom. I'm right here." She only looked at me and turned away asking the same two questions. I don't think she could have recognized me.

"I'm going to get him Mom. It's going to be ok," and with those words said I walked back across the street to get my step-dad for my Mom. A man that was the most literal sense of a monster. A man that had treated me like garbage more than he ever treated me nice. A man that had said I love you to me enough to fill a hand. A man that had tortured my mind and heart for 15 years. A man that had asked me if I was gay, when I decided I didn't want to play football or any sport for that matter, when I was 10ish. A man that never showed up for the things I was proud of. A man that did love me in spite of all those terrible things. A man that had done things for me that my own father never did, or had a chance to do. I loved him then, and I love him now...but I still hate the way he could be. A man that I hated as much as I loved. I went across the street to try to save him, to show him that I was strong, to show him that I loved him.

I walked to the front door with every intention of going right back inside the house, but the heat stopped me. I was still afraid. My fear stopped me from going back into that house, and I think that no matter how much I justify it, that will always bother me. I was told to get away from the door, but no one touched me. I consented, not wanting to be by the fire. I started back to the Master Bedroom window and began calling out to him. "Dad, I'm right here! Follow my voice! I'm right here! Just come to my voice I'll lead you out!"

And when panic really started to get to me and all hope seemed lost I started crying but I never stopped calling out to him. I hope he heard me screaming for him, even when the pain was the worst. I hope he heard me call him Dad for the first and last time in his life. I hope he heard me tell him I loved him. I hope wherever he is now he knows that I did love him, and that I do still. Yes, he could be evil, but I love him for those times few and far between where he was like a father. I'll always love CONTINUED Page 12 "RECOVERY"

BSTTW COMMUNITY NEWS

CONTINUED From Page 11 "RECOVERY" him for that.

There is another black out spot here because I think I don't want to really remember this. I told someone in the hospital, an Aunt, that I heard Terry screaming in the house. I heard him die just as all the windows blew out of the front of the house.

The next thing I remember, and thankfully the last was talking to the fire fighter telling him about my lung surgery, and calling him sir before and after each answer. Old habits die hard. They got me wrapped up in a blanket, sucking up oxygen, and then got me on a stretcher. I was rolled past a few cars and caught sight of my house burning to the ground, water being sprayed through the front door. I knew Terry and Sam were dead-"Where's my Mom?" They told me that she was ok; she was right behind me and asked me not to talk. I was brought into the ambulance where another round of questions and orders was tossed around when a thought occurred to me.

I wasn't feeling so hot. I was in fact feeling really really slow. My energy was gone, the adrenaline wasted, God alone knows how much fluids I lost walking back and forth outside screaming. I was feeling like I thought death would feel like, like drifting off to sleep. I could see the paramedics out of the corner of my eye. They weren't looking at me they were trying to get something straight amongst themselves. When I moved my hand up to move the mask they looked down. Surprise was all I saw on their faces.

I have never been a religious person, and I don't know if I ever will be, but I know that my belief in God changed that night. I looked up at one of them and locked eyes, and said words that have changed my life since that day. I said, "Pray for me...I was a pretty good guy." And then I left reality.

I was taken by Bayflite to Tampa General Hospital, one of the four burn units in Florida. My first few days I was in a drug induced coma. It took me a week or two to have even an semi logical

conversation. Time in the hospital is meaningless to those who are truly hurt. Hallucinations are all that I can remember clearly and they were so incredibly vivid even now, that I'm getting goose bumps.

Family and friends showed up only to be turned away. Very few people were allowed to see me while I was still listed as critical. Biagi showed up that morning after seeing my news story on TV. He was a mess. They made him sit outside for hours before letting him see me. He cried. He told me that I wasn't recognizable to him, that he couldn't believe that what lie in that bed was actually me. He was my best friend, my brother by choice, and he had to leave to go to Germany. He tried to get an extension on his leave, but they wouldn't award it to him because I wasn't immediate family.

Part 2 will be in the January 2004 Issue.

BSTTW CONTACT INFORMATION

BSTTW COMMUNITY NEWS

World Burn Congress (WBC) 2003

By: Michael Appleman

The WBC a time to express Get support & release the stress

Let's reach out to all Pick them up if they fall

Make friends they will remain Enjoyment is a big part of our gain

Help them open up & not regress Ask questions, do not guess

Our lives had changes in such a rough way Look around we are all here to stay

> Seeing a smile on their face No matter what burn or race

Realizing the love from all Helps us to climb the recovery wall

Check the breakouts every day Which ones will direct your way

After it is over what do we say Friendship and support from far away

Pass out contact info A must before you go

WBC 2004 in Chapel Hill, North Carolina for all Come back and remember we will have a ball

Michael Appleman

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 1-800-503-8058. 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

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DONATIONS

As a 501 (c)(3) Non Profit Organization, all donations, big or small are tax deductible to the extent of the law. BSTTW accepts donations for our General Fund, the "Bishop Peter Nguyen Van Nho World Wide Burned Children's Fund", "Dwight Lunkley Racing To Victory" fund, USA, Asian and Middle East Burn Camp funds, Vietnamese Burned Children Fund, BSTTW Religious 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 educating the public from around the world.

Remember your donations can be money, clothes, a used bicycle etc.. Many families loose their homes and property. All will help burn survivors and their family. Please personally think about and talk to your family and friends about donating to BSTTW.

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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, 800-503-8058 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 are in need of support, advocacy, medical supplies and attention, a home, food, clothes, 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** and join the **BSTTW** Volunteer Team. Feel free to contact BSTTW by telephone at 941-364-8457, 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.

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