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# BSTTW Teen NEWS

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## BSTTW OPENING DOORS

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### Bishop Peter Nguyen Van Nho World Wide Burned Children's Fund

By: Michael Appleman, CEO

**B**STTW has changed the name of our burned children's fund to honor a very special individual who has been helping **BSTTW** and all types of people around the world.

Bishop Peter Nguyen Van Nho has been helping **BSTTW** for over one year before his death in May 2003. Michael Appleman, President/CEO & Executive Director and Nguyen Thi Dieu Tran, Vice President & Director Viet Nam, met with Bishop Peter Nho several times during **BSTTW's** trips to Viet Nam in 2002.

In April 2002 Bishop Peter Nho met me for the first time. Bishop Peter Nho learned a lot about **BSTTW** and wanted to take part in helping the burn survivor community and the growth of **BSTTW**. Bishop Peter Nho understood the need people have when they suffer a traumatic injury. During the Viet Nam War, Bishop Peter Nho was helping all individuals in South Viet Nam. He kept the belief in God and continued his studies to better himself and in return help the Catholic Community and all people from around the world.

Bishop Peter Nho, Dieu Tran and I prayed for God's help to build **BSTTW** with guidance, knowledge, strength and funding needed to continue our work with the burn survivor community.

Each time I returned to the United States from Viet Nam, I found more help and information needed to strengthen **BSTTW** and increase the help to the burn survivor community world wide.



After the **BSTTW** Board of Directors heard of Bishop Peter Nho's death, we met and voted to honor Bishop Peter Nguyen Van Nho by changing the name of the **BSTTW** burned children's fund.

All of us need to work together and help the current and future burned children in the USA, Viet Nam and all parts of the world. Burn survivors and family members are an important part of your community and the world. Rebuilding a burned child's life is an important part of the world's future.

**BSTTW** continues the efforts needed to do God's work and reach the prayers and dreams of Bishop Peter Nguyen Van Nho.

## A FAMILY AROUND THE

Please take part and help **BSTTW** rebuild the lives of the current and future burned children by donating to the Bishop Peter Nguyen Van Nho World Wide Burned Children's Fund. All donations are tax deductible on your United States tax return.

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## NUTRITION THERAPY AND BURNS: LET'S BEGIN AT THE BEGINNING..Nutrition Therapy & Burns

By Paula K Burke, RD,LD

It is my great privilege to start a series of articles for Burn Survivors Throughout The World, Inc.. It seems that as I begin this series, a good place to start would be to share with you some of the information that is used by the Registered Dietitian (R.D.) to assess the nutritional status of an individual who presents to the hospital with a severe burn injury. The dietitian uses the nutritional assessment to develop an individualized nutrition care plan. The nutrition care plan includes recommendations for medical nutrition therapy that becomes a part of the overall therapy plan of the health care team led by the physician in charge.

Medical Nutrition Therapy is considered a “supportive” measure. A dietitian is trained to understand that nutrition is the foundation of both the *structure* and the *function* of every cell in the human body. If optimal nutrition promotes optimal function, then the opposite is also true: sub optimal nutrition will not promote optimal function. The definition of ‘optimal’ can vary dramatically by the situation in which the body finds itself. When the body is in danger, as it is when it is threatened by severe illness or injury with severe burns, nutrition plays a critical role.

### THE NUTRITION ASSESSMENT

The nutritional requirements of a person can be very different and depends on the whole person and their situation. The dietitian uses the ABC approach to assess the nutritional status of a person.

#### *A = Anthropometric Measures*

Anthropometrics include Height and Weight. Weight is generally considered in proportion to Height, with an Ideal Body Weight (IBW) being used as a frame of reference. The IBW is based on age, gender, and

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frame size. The estimated daily calorie and protein needs are calculated based on the person’s weight.

It is important to remember that the skin is one of the most important organs in the body when it comes to preventing dehydration. When a large portion of a body’s skin surface is destroyed by burns, it can be very difficult to keep enough fluid in the body and to keep it working properly. Ideally, the dietitian will know the usual weight of the person *before* the burn injury. It is this weight that the dietitian prefers to use because it gives a better idea of whether the person was of normal weight, underweight or overweight before the burn injury. Although height remains the same, weight changes, and can change dramatically when a person has been severely burned. The weight of a person can change up or down by 30 pounds or more because of the amount of body fluid a person has lost or gained. This is because 1 liter of fluid weighs about 2.2 lbs.

This is important to know when calculating calorie, protein and fluid needs. If the usual body weight is not known, the ‘dry’ body weight that is obtained on admission to the hospital will be used for calculations as compared to what is known as the ‘wet’ weight that occurs during or after fluid resuscitation. A dietitian closely watches the weight of the patient throughout the hospital stay.

#### *B = Biochemical Measures*

Blood work is done on all people hospitalized with severe burn injury. The blood that is drawn from a patient is sent to the laboratory where the blood levels of many substances can be measured. What substances are measured depends on what the physician and other members of the health care team want to see. This includes ‘electrolytes’ such as sodium, potassium, calcium, and magnesium as well as different blood proteins. The blood levels of these substances are very important in letting the health care team know how the body is responding to the different therapies being provided. These therapies include medical, nutritional and drug therapy.

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***C = Clinical Indications***

The dietitian also wants to know other important information about the person. This information includes the medical history. The medical history tells the dietitian whether this person was completely healthy before the burn or whether the person has other medical conditions before or since the burn injury. The medical history also lists any medications, vitamins, minerals or other dietary supplements the person may currently be taking or were taking prior to the injury. These facts are very important in helping the dietitian to assess the nutritional status of the patient, develop the medical nutritional therapy care plan and in monitoring the patient's response to therapy.

**THE NUTRITION CARE PLAN**

The care plan is developed to provide adequate nutrition support via medical nutrition therapy with the following goals:

1. Provide adequate nutrition (calories, protein, fluid, vitamins, and minerals) to meet the nutritional needs of the patient. The goal of optimal nutrition is to meet the body requirements of an individual without underfeeding OR overfeeding the patient. Both underfeeding and overfeeding places an undesirable stress on the body.
2. Minimize the loss of lean body tissue. When the body is in a stress response such as with severe burn injury, the body does not use stored fat tissue to provide energy for the body; instead the body starts to break down muscle tissue for energy when the body is in the stress response. When the body is properly fed, the breakdown of muscle can be slowed down.
3. Prevent weight loss of more than 10% of the usual body weight before the burn injury. Some weight loss is unavoidable, but the goal of medical nutrition therapy

is to keep this weight loss to a minimum. In a person that weighs 100#, this would mean that when the person came out of the critically ill phase of the burn injury, the person would not weigh less than 90lbs.

4. Provide adequate nutrition that will assist wound healing and help prevent infection.

The dietitian develops the care plan to meet these goals by calculating an initial or starting point of estimated nutritional needs for a person. The first step in the plan is to reach the point where the person is actually taking in 100% of the estimated needs. For the first 72-96 hours the person will usually not be able to eat and will be undergoing fluid and electrolyte replacement. The person may need to be fed with an IV or feeding tube early on. Until the patient is discharged from the hospital the dietitian will be monitoring the patient in several ways to be sure that the 4 goals of nutrition support are being met. These include:

1. Daily calculation of the amount of calories and protein the person is taking in via a Calorie Count.
2. Monitoring fluid intake and output daily.
3. Monitoring weights that are measured at least twice a week for changes.
4. Monitoring changes in blood work or 'Labs'.
5. Monitor the progress of wound healing.
6. Monitor for signs and symptoms of infection.

The dietitian will recommend to the physician any changes in medical nutrition therapy that would be appropriate and desirable for the patient.

We have now come to the end of the beginning, which is the period of time immediately after the severe burn injury when the patient is in the critically ill stress response phase. This is the period of time where the person may be unconscious or sedated to the point where they may be unaware of what is truly happening to them. The nutritional needs of the patient do not go away after this beginning however,

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as you well know. The ability to take in enough calories and protein can be very challenging. Next time we will discuss ways and means to achieve this. This is when the person is actually eating real food on their own again, whether in the hospital or at home!

## Tai Chi and Your Recovery

By: Matthew Rockford, BA

Tai Chi was originally practiced as a system of self defense which incorporated the Taoist philosophy of Yin and Yang (harmony). This unique art has over the years evolved to become one of the most popular forms of holistic exercise systems in the world and is now used by many health professionals to help patients restore their health and vitality. Because the movements are all done in a slow, relaxed manner at the students pace it is especially good for anyone with limited mobility or in the process of rebuilding their lives. There is no pressure with Tai Chi and no set targets other than those you set yourself, so a program can be designed to suit you, depending on your personal desires and range of mobility.

Since the beginning of time, human beings have been practicing exercises and forms of meditation designed to improve well-being and restore health. Since the 1700's, the Chinese have been practicing an art known as "Tai Chi Chuan". Tai Chi Chuan is characterized by its soft, fluid movements and many relaxing effects. It has since come to be known as a form of moving meditation. Nowadays Tai Chi is used the world over to help in the fight against stress (in all its forms) and the improvement of inner and outer health. By "inner health" I am referring to the mind and by "outer health" the body and it is on these two axes that Tai Chi can bring real and lasting benefit to those who have recovered from the worst affects of burns. The beauty of Tai Chi as a system of rejuvenation is primarily its flexibility and adaptability to suit all ranges of mobility.

In China the philosophy of recovery includes using movement based therapies to help the body heal

itself (along with acupuncture and herbal medicine). This placement of value upon keeping the individual's body and vital energy moving in relaxing yet stimulating ways is becoming more accepted in the West. It is no surprise that Tai Chi is being used in hospitals, community centers and colleges on a more regular basis to help people from all backgrounds improve their health in a more interactive way. Tai Chi offers the individual a flexible program which they can adapt for themselves which offers both physical and mental benefits

The movements of Tai Chi are all done slowly to aid in the relaxation of both body and mind. The most noticeable affect is that of mental calm as the mind is focused in the present moment free from distraction and worry. The gentle movements meanwhile help to promote blood flow throughout the body and lymphatic stimulation (thus boosting the immune system). The qualities of improved blood and lymph flow can aid in the recovery from many conditions and may help in tissue healing as well as a general feeling of well being and warmth within the body.

The movements may also improve the oxygenation of the blood, as the posture adopted in Tai Chi improves lung capacity and efficiency. This in turn is good for our brain power which will benefit anyone! Tai Chi may also help with improving elasticity of the skin due to the tissue being very gently stretched (but never forced) during movement. This therapeutic movement will also help raise the mobility in the joints (fingers, toes etc) which will be especially useful for burn recovery.

Socially Tai Chi classes are great for meeting others with a common interest in well being and in my 12 years of experience are usually attended by non-judgmental people who are, dare I say it, really nice people. As I imagine, recovering from serious burns, may affect an individual's social level to a higher degree, due to all our social stigma on how we look, then a class which provides some support and space with the idea of "just to be yourself". Just to be yourself, may be useful in the recovery of confidence and self esteem. The confidence gained from practicing and perfecting the movements has also, in my experience, both as student and teacher, helped

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many people gain a new type of confidence in their bodies (with new levels of kinaesthetic ability) and boosted self esteem and mental well being.

I wish you well!

Matthew Rochford is the director of The Devon School Of Tai Chi in the United Kingdom. Mr. Rochford is also the author of the book "Total Tai Chi".

## Your Road to Success

By: Delores Gempel Lekowski

As a loyal fan of, "American Idol™," I couldn't help but think how fortunate these talented singers are to be given the chance to share their talents with the world and obtain instant success and notoriety. Wouldn't it be wonderful if there was a program that would showcase all of our talents and propel all the worthy contestants into stardom and fame? Since most of us don't have a great singing voice, being discovered on American Idol isn't an option for us. I guess we will have to find our own way using hard work, determination and drive. Don't let this discourage you, after all, half the fun of getting somewhere is the trip along the way and if you are doing something you enjoy, it isn't work, it is in itself, success!

What are your talents and passions? Have you given any thoughts on how you will achieve success using your talents? It is never too soon to think about this, the sooner you start the sooner your dreams will become a reality. Do you think if there was a program that allowed you to showcase your talents, it would propel you into success?

If we could design our own program what ideas on starting and implementing the program could you offer? What are your talents and passions. What do you enjoy doing and you are good at? For you guys, maybe your dream is building a racecar or a house. Maybe you gals would love to decorate that house or drive that racecar! Maybe it is neither of these things. Maybe it's singing, dancing, acting or becoming a political powerhouse? Do you want to change the world or entertain it?

How would you showcase your talents? How will you get your name out there? What do you think would be the single greatest thing that would help you? If I could construct a road to success, where would you like the road to take you? Who and what do you think would be beneficial for your trip to success? If you wanted to be a fashion designer would it be helpful to personally get advice from a famous designer? What about that future country singer, would a trip to Nashville encourage your dream? Would a personal visit with a famous writer empower a beginning writer? Wouldn't it be nice if someone who has already achieved the same dream you are seeking, took you under his or her wing? If there was one central place you could go and have arrangements made to personally meet with your biggest role model, would this be beneficial to your future career? Would this make it easier for you to reach for the stars and maybe even catch one?

It all sounds wonderful doesn't it? If all this were possible, what talents would you want to cultivate and how could someone help you do this? Tell me about yourself, I want you to give some serious thought to your dreams and how you plan to realize them. Compose a map you think would be useful to finding your road to success and tell me who you would like to connect with along the way. What are your thoughts and ideas on how to construct a road that would help you and others with the journey to success? Let me know what you think would be the single most valuable source to help you realize your dreams. Send me an e-mail with your thoughts and the details about your dreams to [dlekowski@neo.rr.com](mailto:dlekowski@neo.rr.com). I think sharing your dreams and ideas would be a fun project. If I receive enough ideas I will share them with everyone in my next teen article, so please, lets help each other reach for the stars.

Happy Dreaming.....

## Could It Have Been Different?

By: Mary Ellen Copeland, MS, MA

I first became aware of "mental illness" when I was eight years old. My mother began spending all of her  
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time sitting in a rocking chair-rocking, crying, very frightened and unbearably sad. No one asked her why she was crying. No one took the time to sit with her and hold her hand. Instead they took her away to a mental institution. That's where she spent the next eight years of her life. This brilliant woman with a degree in nutrition, ahead of her time in her understanding of the effects of food on the body, deeply caring and compassionate, was treated with 150 electric shock treatments interspersed with various experimental drugs available at the time to stop her sadness. She spent her days behind a series of thick locked doors, sharing a sleeping and living space with 50 other women, in a dark, smelly ward with no privacy-50 beds in one room with only the space for a small night stand between. They wondered why she didn't get better, why she kept crying. Instead she got worse. Instead of just crying, she started wringing her hands, walking in circles repeating over and over, "I want to die." Several times she tried to kill herself. Sometimes she was very different. She would be racing all over the place, laughing hysterically, behaving in a bizarre manner that made us even more frightened than we were when she was depressed.

I know this because every Saturday morning for eight years, I went with my three brothers and sister to visit her. It was a truly frightening experience. This was not the person we had remembered as our mother. They told us she was incurably mentally ill. They told us not to bother to come and see her anymore. But we did. She still remembers that the next time we came to see her after they told us not to come and see her anymore, we brought her a big bouquet of gladiolas.

Something strange happened. A volunteer noticed she wasn't having these episodes anymore. She was even helping to take care of the other patients. She still wonders if it had anything to do with that volunteer who sat with her for hours and listened to her, even took her for some rides. She says she kept apologizing for going on so, but the volunteer said to go right ahead. So she kept talking. She talked and talked and talked. Then she got herself discharged.

This incurably mentally ill woman came home to her family, got a job working as a dietitian in the public schools, kept that job for twenty years while keeping up with the activities of her ever growing family of children, grandchildren, and great grandchildren. She's now 82 years old. Thirty-eight years ago she got out of the "hospital". On many days I feel as if she has more energy and enthusiasm for life than I do. She's never taken any psychiatric drugs. Incurably mentally ill?

She will never remember what it was like when we were little. Her memory of those years was wiped out by electro shock. She lost 8 precious years of her life and had to overcome the stigma faced by any person who has spent time in a mental institution.

Sometimes I fantasize about my mother's life. How might this story have been different? Suppose when Mom said that she wanted a part time job-just before this sadness and crying started -Dad had said, "Sure Kate, what can I do to help?" Suppose her women friends and her lovely Pennsylvania Dutch family had gathered around, listening for hours on end, holding her hand, empathizing with her, crying with her-then what would have happened? Suppose they had offered to take the kids for a day or two, or a week, or a month so she could do some nice things for herself. Suppose they had offered her a two week cruise in the Caribbean. A daily massage. Suppose they had taken her out to dinner and a good movie, a play or a concert. Suppose someone had told her to get out and kick up her heels, to read a good book, go to a lecture on the importance of good nutrition. Suppose, suppose, suppose.....

Maybe I would have had a mother when I was growing up. That would have been nice. My brothers and sisters would have liked one too. I'm sure my Dad would have liked to have a wife and my grandmother would have liked to have her daughter in her life. Most important, my mother would have had herself, with all her memories intact.

Suppose, 20 years ago, instead of going to the psychiatrist to be told that mental illness is hereditary and I have the same disease as my mother, I had

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searched out my friends to hold me and listen while I cried and laughed. Suppose my husband had said, "Don't worry, Mary Ellen, I can handle things. Just take a break. You deserve it." Suppose the family had pooled their resources and sent me on a hiking trip to the White Mountains or encouraged me to take some much coveted courses, or taken me out to lunch and for a bike ride, or to pick flowers, or brought me a kitten. Suppose the house had been decorated with beautiful flowers. Suppose I had had my own little space to go to whenever I wanted and do what I needed to do for myself. Suppose I had known that I had some value and could do for myself whatever it was I needed to make myself feel better. Go to every movie playing for a month. Whatever. Just suppose.

Maybe I wouldn't have spent too much of my life in mental institutions looking for ever elusive answers to my pain, too many years with my brain in a drugged fog, too many years of deep sadness and suicidal ideation interspersed with periods of outlandish behavior. It has taken me years to undo the damage. Maybe there would be no tremor in my hands, maybe some of the relationships that ended for me during those hard years would still be part of my life. Maybe my career and reputation would have remained intact instead of having to start all over again at 50.

Through all those foggy years something was stirring in me. Something that knew somehow that all of this was not right. Something that caused me to ask my psychiatrist how people deal with these illnesses on a day to day basis. He said he would get me that information. (Finally a promise of some useful help) When I returned the next week in great anticipation he told me no such information had ever been gathered. The only information he could give me was on psychiatric treatment, medication and restraint. From someplace deep inside me a voice kept saying "this is not right". The voice got louder and louder.

For the last four years I have dedicated my life to finding out how other people cope, and the more I learned, and put this learning into practice in my own life, the better I felt. I learned that there is a silent

but very courageous group of people all over the country who, like me, have been told that they are incurably mentally ill. These people have not given up. They have found the way out of the maze and I have become the vehicle for getting their important messages out to the rest of the world. I gather the information and spread it as far and wide as it needs to go. Through seminars, lectures, books, videos and grass roots networking.

This is the most important thing that I have learned: people being there for people creates more wellness and more recovery than anything else. The next time you start feeling low (or high or strange), reach out. If someone you love is having "psychiatric symptoms", sit with them, listen to them, let them cry, scream, shout, swear. Don't judge them. Don't criticize them. Hold the advice. Just be there. Bring them good food or flowers. Take them away to a place of beauty where they can rebuild their strength. Do for them what you would like to have done for you.

**Today, Tomorrow & Yesterday**

By: Michael Appleman

**Today is a day that I wish never came  
There is no one that I can blame  
I feel that I will never get off this train**

**Yesterday was better in so many ways  
I understand how good were those days  
Can I ever get back to those ways**

**What will tomorrow bring  
Will I loose every thing  
The burn it continues to sting**

Michael Appleman

**BSTTW CONTACT  
INFORMATION****Emergency Contact**

We have an Emergency Email Form on the Internet.  
Go to: [www.burnsurvivorsttw.org/emergemail.html](http://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”, Asian, Middle East & USA Burn Children Camp funds, 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**. Federal Tax ID #94-3403785

#### **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](http://www.burnsurvivorsttw.org/donations.html)

### **BSTTW TEEN NEWS**

If you have any questions call us at 941-364-8457, 800-503-8058 or email **BSTTW** at:  
[donations@burnsurvivorsttw.org](mailto:donations@burnsurvivorsttw.org)

### **Volunteering Your Time With 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](http://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, 800-503-8058 or email us at [volunteers@burnsurvivorsttw.org](mailto: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](http://www.burnsurvivorsttw.org/sales.html)

You can also purchase Skin Care Products by telephone at 800-503-8058.

### **BSTTW ADDRESS & PHONE NUMBERS:**

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