



MITSS NEWS

SPRING 2004

“To Support Healing and Restore Hope ”

MEDICALLY INDUCED TRAUMA SUPPORT SERVICES, INC.: WHO WE ARE

Medically Induced Trauma Support Services (MITSS), Inc. is a non-profit organization founded in June 2002, that supports, educates, trains, and offers assistance to individuals affected by medically induced trauma. MITSS's mission is to promote healing and to restore hope to these individuals and their families and to engage in other activities that support the above stated purposes. We define medically induced trauma as unexpected complications due to medical/surgical procedures, medical/systems errors, and other medical circumstances that result in a negative impact to the overall well being of an individual and/or his or her family members. Further, we are committed to providing support for health care professionals, and we are exploring how best to meet the emotional needs of medical staff involved in a medical trauma. Finally, our goal is to educate and inform hospital administration and staff of the need for and availability of our services.

MITSS FIRST THERAPEUTIC EDUCATION GROUP HELD AT BRIGHAM AND WOMEN S’

MITSS is very pleased that our first structured Therapeutic Education Group was held this past fall. Brigham and Women s’ Hospital in Boston generously provided us with the space for the group to meet at their 850 Boylston Street site in Brookline.

The group experience consisted of six two hour weekly sessions and was comprised of both patients and family members who had personally experienced a medical trauma. Dr. Jean Bellows, a licensed psychologist with over thirty years of experience dealing with trauma, led the group. The purpose of the group was twofold -- (1) to educate its members in recognizing symptoms of and understanding post traumatic stress; and, (2) to support healing for each person s’ negative event through the therapeutic process. The group was supplied handouts looking at the various stages of trauma and grief.

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ANNUAL FUNDRAISER AND SILENT AUCTION HELD AT SONESTA

The MITSS Annual Fundraiser and Silent Auction was held on Friday evening, November 7th, 2003, at the Royal Sonesta Hotel in Cambridge, Massachusetts. The festivities began at 6 p.m. with the unveiling of the silent auction items accompanied by hors d'œuvres and cocktails. Guests enjoyed bidding on their favorite items which included two round trip plane tickets to anywhere in the Continental United States provided by USAIR, a print on canvas provided by Thomas Dunlay, and various sports memorabilia pieces donated generously by the New England Patriots, the Boston Bruins, and the Boston Red Sox organizations.

Once the bids were in, we convened to the dining room for a sumptuous meal. Entertainment was provided by *Burnt Toast*, a multi-talented, versatile band based on the South Shore who specializes in providing music for special events.

MITSS was honored to have Roxanne Goeltz of Lakeville, Minnesota, as our featured speaker. Ms. Goeltz is a consumer advisor to Partners for Patient Safety (P4PS) and the University of Chicago Safety Group (UCSG). She is also a founding member of Consumers Advancing Patient Safety (CAPS). Ms. Goeltz has had first hand experience in surviving a negative medical outcome. She spoke eloquently and poignantly about her brother's untimely death and her family's frustration with their inability to get answers as well as their struggle to move on from their tragedy. She noted that in her own personal experience, she could have



Linda Kenney and Roxanne Goeltz at the MITSS annual dinner.

benefitted from an organization like MITSS that offered support to families such as her own.

The evening concluded with the announcement of the top bidders for the silent auction items. Ethel Boyd, MITSS Executive Director, also announced the winners of the various raffle items donated to MITSS by local merchants. Raffle winners received restaurant gift certificates, certificates for manicures, and a "tailgate" package including a portable gas grille and sports chair, to name a few. It was an evening of good food and good fun, but most of all great people gathered together for a great cause. See you next year!!

**THANK YOU,
WAL-MART GOOD WORKS
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A Patient's Story...

At the beginning point of this journey the very thought of discussing the trauma I had experienced felt entirely beyond my capabilities. My survivalist's instinct was to tuck the entire ordeal neatly into a far corner of my mind; or better yet to pretend it didn't happen at all. Soon though it became apparent that that approach wasn't working. Daily functioning became an overwhelming task. The harder I tried to forget, the more daunting everything became. Every aspect of my fairly predictable life was now a thing of the past. How was I going to deal with a world that was so foreign to me?

At the urging of my primary care physician I sought counseling as a way to attempt to put some order back in my life. I attended the first counseling session enthusiastically. I was looking forward to being instructed on exactly what steps I needed to take in order to regain control in my downward spiral. I guess I thought that somewhere there was a manual, that listed steps 1-10, sitting on the counselor's shelf just waiting for this particular patient to use. Surely all I had to do was follow these golden rules of recovery and all would be well. Unfortunately, my expectations of counseling were as unrealistic as the world I was forced to live in daily. It became apparent all too quickly that my foolproof method of recovery would require a lot more hard work than I had planned on. After weeks of some emotionally charged days and nights I finally felt I was making some real progress. Dealing with the grief, anger and betrayal associated with the loss of my unborn baby at the hands of a medical community I had been taught to trust was a painstaking task, but one I had made some positive strides in addressing. I discontinued the therapy sessions some months later.

Still there were some long-term issues which I couldn't quite understand or put my finger on. Frequent terrifying nightmares, checking numerous times to make sure all the windows and doors were securely locked, freezing at the sound of an ambulance siren and avoidance had all become deeply ingrained. These constant fears pushed me to seek out additional resources to help me to recapture the person I had once been. Perhaps the biggest fear that motivated me was that I did not know the person I was becoming.

I began counseling anew with a therapist that by chance, and much to my good fortune had specific training in trauma. She helped and encouraged me to take control of the roller coaster that up until this point I had felt was my destiny. I gained the knowledge that I could again be in control of my future; I just needed to take the positives I did possess and work with them in the context of the trauma. The fear of being emotionally hurt again was a large factor in what had been holding me back from making any forward progress with the long-term issues. After some time I came to learn that I had already been to the worst place in my life that I ever imagined possible; there was no worse place to fear.

After having dealt somewhat with the emotional fallout of my trauma I felt the next step was to somehow connect with others who had experienced a similar situation. I began to seek out some additional resources that dealt specifically with medically induced trauma. My quest began by contacting Senator Moore's office and requesting information about the Betsy Lehman Center.

I was told that the Lehman project had had the funding cut and was not operational.

I was then referred to Paula Griswold at the Massachusetts Coalition for the Prevention of Medical Errors. During a lengthy conversation with Paula she informed me about a group called MITSS, and gave me Linda Kenny's phone number. My conversation with Linda was the first time I had actually talked with anyone who had also dealt with medical trauma. I knew immediately that becoming involved with MITSS was the next logical step to take in my recovery. Not only had Linda offered a compassionate ear, but also for the first time in the past year and a half, I was convinced that someone really understood what it felt like to undergo such an ordeal. I was very excited to be interviewed for the support group that was being started, and desperately hoped that I would be a good fit for the group, and likewise that the group would be a good fit for me. After the first group meeting I instantly felt a bond with each and every person in that room, unlike any I had known before. Those bonds only continued to strengthen as we went around the table and 4 other women shared their heart rendering experiences. I received a special gift that night and at each of the following 5 meetings. That gift was validation.

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A Patient's Story Continued

What I found was that the emotions I had experienced were a common thread we all shared - maybe not exactly in the same way, but just as deeply. Through the materials and knowledge that Jean Bellows so carefully shared I slowly came to know that all of the emotions and feelings that follow such a loss and/or trauma were all normal things to have felt. Some were in fact the body's healthy way of coping with an overwhelming experience such as we all had had. I gained a better understanding of the sequelae inherent in Post Traumatic Stress Disorder and the profound effects it had on both my conscious and unconscious being. Education was provided that explained the hows and whys of the physiological processes that occur when someone deals with trauma. She explained ways to make situations that feel uncomfortable more bearable and not so out of our control or helpless feeling. Everyone listened to each other in a non-judgmental, empathetic way. The ability to trust was an issue that I had continually struggled with. Again, I quickly came to find this just wasn't something I had to worry about within this group. We were all in the same boat just with different oars by our sides.

Our conversations at the Tuesday night meetings encouraged and strengthened my conviction to continue the same dialogue at home. I felt empowered to talk more openly about my trauma with my husband. I had never fully understood his reactions or better yet how he was able to let it go so seemingly easily after he got over the initial shock. This had never been an easy topic of conversation to discuss with him as we both approached our grief from very different directions. That piece kept coming up time and time again and was a very painful part that up until that time was never adequately explored. I believed he just didn't get it. "He thought, 'Why isn't she getting over this.' What came to light after our talk was something very different and came from a perspective that I had never been attuned to. To my husband, after witnessing my being rushed to the hospital by ambulance with Advanced Life Support, being told he could not ride with me, not being given any answers when he reached the hospital, and then the worry of recovering from emergency surgery - he experienced a tremendous sense of relief and was just thankful that I was alive. To him that was the most traumatic part of our experience and when that aspect was over and he knew I would recover well physically he went on with his life. I was finally able

to understand why he had reacted the way he did to our loss - something I so desperately needed to know. Being able to understand his position felt like a huge weight had been lifted from my shoulders.

Many more pieces came together for me through this support group not only through the camaraderie and encouragement, but through a deeper understanding of what Post Traumatic Stress Disorder entails, and helpful ways in which to further climb out from under its frightening grip.

I consider my being included in this group a godsend that helped me further along in my road to recovery. I don't know where the next step will take me, but I hope someday soon to be able to reach out to others who are dealing with the painful aspects of Medically Induced Trauma so they too know they are not alone. I can truthfully say and feel now, with conviction, that I will never forget, but I need not always remember."

-Jane M.

First Therapeutic Education Group

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We were able to create a safe space for each group member to share her story, her sense of isolation, and an opportunity to feel validated. Individually, everyone was able to identify their own emotional triggers and to look at various tools that would enable them to deal more effectively with the feelings that follow those triggers.

As it is our mission to bring healing to those who have suffered from an unexpected medical trauma, MITSS was quite pleased to receive much positive feedback from our first Therapeutic Education Group. One of the group members was kind enough to document her experience (see **'A Patient's Story'** above). MITSS will be starting its second Therapeutic Education Group in April. For more information, call us at 1-888-36MITSS or visit our website www.mitss.org.

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MITSS AND DANA FARBER COLLABORATE IN SPONSORING CLINICIANS ' WORKSHOP

MITSS, together with the Dana Farber Cancer Institute, recently sponsored a workshop entitled Forum: Improving Clinician Support Systems for Adverse Medical Events. The Forum was held on January 6th, 2004, at the Dana Farber. The purpose of the conference was to brainstorm regarding the effects on medical professionals in cases of negative outcomes and to further MITSS's commitment to providing support not only for patients and families, but for clinicians as well. The conference was attended by physicians, nurses, and administrators working in local health care settings.

Linda Kenney opened the workshop by relating her own story from a patient's perspective and the resulting impetus for starting MITSS. Rick van Pelt, M.D., the anesthesiologist involved in Linda's adverse event, then addressed the group. He detailed his own experience from the physician's point of view, speaking about the administrative procedures that were followed at the hospital where he practiced as well as the emotional impact he suffered from the event. John Fromson, M.D., Vice President of Professional Development at the Massachusetts Medical Society, spoke about Physicians Health Services (a non-profit corporation founded by the MMS) that provides confidential consultation and support to physicians, residents, and medical students facing health concerns related to substance abuse, mental health issues, and physical illness. He related his experience in dealing

with stressors unique to those serving in the medical profession. Miguel Leibovich, M.D., a psychiatrist currently treating physicians involved in malpractice lawsuits, then shared his expertise with regard to the emotional fallout doctors experience when dealing with medical errors and adverse outcomes.

The presentations were followed by a group discussion focusing on what support services are currently available to clinicians, clinicians' general awareness of the services being offered, and what steps could be undertaken to improve the current systems. It was agreed that any plan would be most effective if put forward with a multi-disciplinary approach. It was also suggested that additional research would need to be done to more fully identify how best to support health care professionals in cases of adverse events. MITSS is currently involved in discussions regarding the setting up of such a research study.

It was the general consensus of the participants that a cultural change would have to slowly be effected in order for MITSS's ultimate goals of acknowledgment and support to be realized. The next steps in our efforts to bring services to clinicians will include sponsoring another conference and brainstorming session scheduled for the spring, participation in a research study focusing on issues unique to those in the medical professions, and our continued outreach to the health care community encouraging open and frank discussion regarding adverse events and the critical need for our services.

LINDA KENNEY TO PRESENT AT FORD HALL FORUM

The Ford Hall Forum in collaboration with the Massachusetts Medical Society will be sponsoring a panel discussion *Medical Errors and Patient Safety: Where are We Now?* to be held on Tuesday, May 11th, 2004, at 6:30 p.m. at the Massachusetts Medical Society, Waltham Woods Corporate Center.

The Institute of Medicine reported in 1999 that health care in the United States is not as safe as it should be and that as many as 98,000 patients may die each year from preventable medical errors. This forum seeks to address *How far have we progressed in five years? How do doctors, nurses, and other health care workers approach patient safety? What is the responsibility of the patient for patient safety? How can we make medical care better?*

MITSS's president, Linda Kenney, will join a distinguished panel including Lucien Leape, M.D., of the Harvard School of Public Health and an author of the Institute of Medicine's landmark 1999 report; and Connie Crowley Ganser, President of the Massachusetts Coalition for the Prevention of Medical Errors and Corporate Director, Performance Improvement and Compliance, Children's Hospital, Boston. The panel discussion will be moderated by John Fromson, M.D., Vice President of Professional Development for the Massachusetts Medical Society.



Linda Kenney and Frederick van Pelt, M.D.

LINDA KENNEY AND FREDERICK VAN PELT, M.D., SPEAKERS AT NATIONAL PATIENT SAFETY FOUNDATION ANNUAL CONGRESS

MITSS President, Linda K. Kenney, along with Frederick van Pelt, M.D., member of MITSS Board of Directors, will be presenting at the National Patient Safety Foundation's (NPSF) Sixth Annual Patient Safety Congress to be held in Boston May 3rd through the 7th. The theme of this year's Congress is *Let's Get On With It: Improving the Safety of Patients.* The five-day Congress will include more than 80 sessions that offer a powerful blend of knowledge and experience on a wide range of relevant patient safety topics. Program sessions will focus on recommendations and research that promise to bring about cultural change, effective resource management, and the search for excellence in healthcare organizations (www.npsf.org).

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NPSF CONGRESS

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A plenary session entitled Patients, Family, Clinician Partnerships that Change Culture: The MITSS Story is scheduled for Wednesday, May 5th, at 3:30 p.m. Roxanne Goeltz, Co-Founder and President of Consumers Advancing Patient Safety and a member of the NPSF Patient Advisory Council, will begin the session by sharing the details of her family's loss of a loved one and their subsequent search for answers and support. Linda Kenney and Dr. van Pelt will speak about their experience from both a patient's and a physician's perspective, how they overcame the usual barriers to share emotional support with each other, and the resulting creation of MITSS. For more information about the Patient Safety Conference, visit their website at www.npsf.org.

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