Ν L E A E S Η Ι

Inside: **Special Issue**

2003 Macaluso Awards: a celebration of excellence

he Stephanie M. Macaluso Award Ceremony 1 Macaluso, RN, Excellence in Clinical Erica Edwards, RN 2 Practice Awards have become one of the most Kimberly Stewart, CCC-SLP .. 4 anticipated, revered, and emo-Cynthia Thibodeau, PT 6 tionally charged events on the MGH calendar. And if you Mara Wernick Robinson, PT .. 8 don't believe it, just ask this year's recipients: Erica Edwards, RN;

Stewart, CCC-SLP; Cynthia Thibodeau, PT; Mara Wernick Robinson, PT; and Brenda Whelan, RN. Senior vice president for Patient Care, Jeanette Ives Erickson, RN,

Kimberly

creator of this award (first presented in 1996) opened the ceremony by reciting the dictionary definition of the word, 'excellence.'

"Of the highest or finest quality," said Ives Erickson, "something that is excep-

tionally good; superior; worthy of distinction, greatness, or exaltation; perfection. No wonder this award is so coveted."

January 8, 2004

Ives Erickson shared the basic principles of excellence put forth by Tom Peters, noted management consultant and author of, In Search of Excellence and Re-Imagine: Business Excellence in a Disruptive Age. Peters' basic principles of continued on page 12

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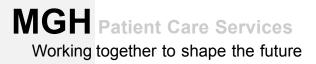
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> Macaluso recipients (I-r): Erica Edwards, RN; Cynthia Thibodeau, PT; Mara Wernick Robinson, PT; Brenda Whelan, RN; and Kimberly Stewart, CCC-SLP, with MGH president, Peter Slavin, MD, and senior vice president for Patient Care, Jeanette Ives Erickson, RN (right).





rica is a graduate of the Whidden Memorial Hospital School of Nursing and has worked at MGH for the past 24 years. She has practiced in the Cardiac Care Unit (CCU) for the past 16 years, where she is a permanent night nurse. Erica has spent her career at MGH caring for patients with cardiac disease; she was on the team that cared for the first MGH patient to receive a balloon pump; and she continues to care for patients receiving cutting-edge treatment and interventions.

Clinical Narrative

Last spring, I had the privilege of caring for a patient in the CCU who was diagnosed with endstage cardiomyopathy due to amyoloidosis (a metabolic disorder). Mr. D was in his 70s, had had a recent biventricular pacemaker inserted. and was experiencing worsening renal failure. He was admitted to my unit for tailored therapy using inotropes and diuretics. Mr. D's cardiac function had continued to deteriorate, and his congestive failure required him to be intubated and later to have a tracheostomy. Poor cardiac output lead to poor renal flow and anasarca (severe swelling) so his care plan changed from stabilizing of his cardiac status to supportive endof-life care.

Mr. D was greatly admired by many who knew him. He had lived the American dream, a real rags-to-riches story. He never forgot where he came from and gave back generously to his community. He was a tough businessman who paid meticulous attention to every detail. I listened to many stories about him from doctors who had known him for years. His greatest admirers, though, were his family.

I met them for the first time when I was assigned to Mr. D shortly after he was admitted to our unit. During his hospitalization, I got to know his wife, his three daughters, and his son fairly well since they rarely left his side. They slept in the hospital, appeared in his room at sun-up, and stayed until well after midnight. Mr. D's children appeared to be professionals. It was obvious they cared deeply for the patriarch of their family. His wife was a quiet woman who didn't share her feelings often, but seemed overwhelmed by her husband's condition. The children were very supportive of her and did their best to attend to her needs while they were here.

According to his family, it was Mr. D's wish that everything be done to prolong his life. To ensure that this was the case, the family educated themselves as much as possible in all aspects of his illness and treatment. It was their feeling that the most accurate information came from the more experienced members of his healthcare team. Almost every doctor and nurse who entered his room was questioned about his/her background and experience as well as Mr. D's condition. Answers were gathered, discussed, and compared with previous answers. There was a general feeling of distrust of newer nurses. To help diminish that feeling, it was decided to try to maintain continuity of care to reinforce their sense of trust. This also helped me become more familiar with Mr. D's care as it had become increasingly complex as time went on.

Over the next few weeks, my greatest challenge was to help this family accept the inevitability of Mr. D's death. Initially, he was able to stay awake for short periods. Whenever he awoke from sleep, he would smile when he saw the loving faces of his family. For a short time, he was able to communicate with them, but after a while all he could do was open his eves and hold their hands. I took my cues from Mr. D regarding the amount of



Erica Edwards, RN staff nurse, Ellison 9 Cardiac Care Unit

time to allow the family to visit. He was truly glad they were there and seemed anxious when they were gone. Because of this, I allowed them liberal visiting privileges when I cared for him. To lessen their need to be with him. I would schedule times for routine care, tell them in advance how long it would take, and try to adhere to that time frame. This helped the family to take breaks and feel comfortable planning to return at a certain time. This worked fairly well for them.

Mr. D's wife had developed a quiet acceptance of his dying, but was becoming increasingly fatigued. She would nap in the chair in his room and the children would try to get her to eat. We all kept a close watch on her as she refused to leave her husband for very long. The children held out hope that their father would stabilize. His son expressed frustration that more

could not be done. One daughter seemed to be carrying a burden of guilt feeling she should have had her father admitted to the unit sooner thinking the outcome would have been different. I listened to each of them and was supportive, assuring them that we were giving our best effort to care for Mr. D while at the same time educating them about the progression of his illness. He was truly a fortunate man to have a family who loved him so much.

Mr. D's care became more time-consuming as he began to retain more fluid. He became very edematous, with fluid escaping through his skin, making him constantly wet. I elevated his extremities with pillows, but this had little effect. I tried to wrap his legs, but even with loose wrappings he would lose his pulse. His legs became so swollen that he developed skin tears requiring continued on next page frequent dressing changes. He developed herpes sores around his mouth so that even mouth care became unbearable for him (medications helped a little, but the sores never went away). He developed lesions on his back that were also diagnosed as herpes. I started using burn vests on his back to wick away moisture. His family was concerned about the frequency of his dressing changes, so we taught them how to change the pads under his arms and legs. This helped give them some sense of control over their father's care.

About a week before his passing, Mr. D started to require maximum ventilator settings and pressors. Now, when he woke from his naps, he no longer smiled; he grimaced. Though he always said he was comfortable when he could communicate, I knew that this had changed. A fentanyl drip was started to keep him comfortable, especially during dressing changes. Once he started on the fentanyl, he rarely opened his eyes or squeezed his family's hands. This was a hard adjustment for them, and possibly, when they started to realize there was nothing more that could be done, and that Mr. D was dying. They grieved more openly, which let me know that after these several weeks of working with them, they would not press for a full code when the time came.

I was grateful to have been working the night

Mr. D died. His blood pressure slowly fell and eventually he lost his paced rhythm. His passing was peaceful, with his loved ones at his bedside. Other family members came in whom I had not met, as well as many doctors who had known him for a long time. He was an extraordinary man with an extraordinary family, and I felt privileged to have helped them.

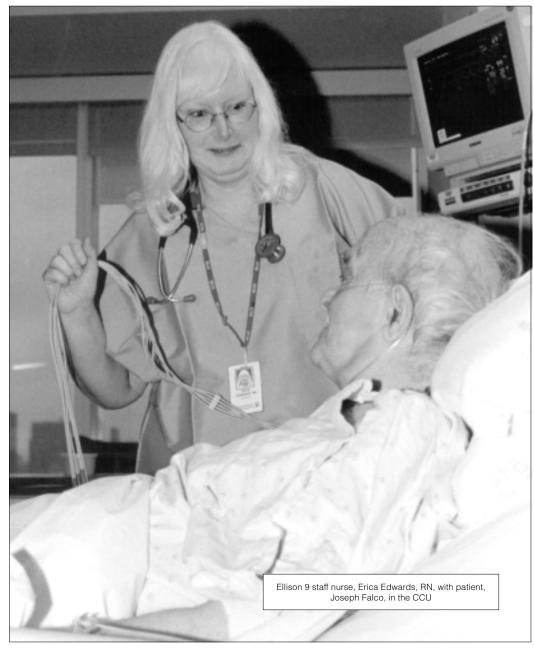
Comments by Jeanette Ives Erickson, RN, MS, senior vice president for Patient Care and chief nurse

Erica helped this family to say good-bye to their

beloved husband and father. She welcomed the family's involvement and brought them easily into the scope of her care.

Erica understood their fears and concerns and devised a system to help allay those fears. She was an experienced 'guide' through unfamiliar territory who made the unknown a little less frightening for this family. She knew Mr. D would not survive this admission, and she gently brought the family to this realization. Erica's presence helped Mr. D and his family achieve a 'good death.'

Thank-you, Erica.





im is a graduate of Mount Holyoke College. She studied in Germany on a Fulbright Grant before graduating from the MGH Institute of Health Professions with a master's degree in Communication Sciences and Disorders. She has been a speech-language pathologist at MGH for two years working with children and adults who are referred with a wide variety of comprehension and communication disorders. Kim is tireless in evaluating, treating, and following up with all her patients.

Clinical Narrative

Twenty-two-year-old, 'Sarah,' arrived in the Speech-Language Pathology Department with incredible motivation, determination, and the most severe developmental, language-based learning disability I had ever encountered. Sarah's cognitive testing described her skills as significantly below average. There was no way around it, and that could have been the end of the story.

But Sarah had incredible social skills. Her abilities in this area were so strong that both adults and children in the waiting room flocked to her. At home, where she lived with her parents, she had friends, a boyfriend, and interacted like any young adult—although superficially. Privately, she admitted she sometimes couldn't keep up with conversations. She knew she didn't have the same job potential that her friends did. In fact. she was very aware she wasn't nearly as independent as they were. She wanted the normal things in life. She wanted to be tired at the end of the day. She hated knowing this wasn't her reality, and her awareness of that reality drove her to do something to make a change.

Sarah's parents were exhausted from battling against Sarah's learning disability but continued to persist. They felt strongly that even though Sarah had finished her formal schooling, her education could not end there. Her academic experience had failed her-even the specialized school she had attended for students with learning disabilities had not helped Sarah sufficiently, and offerings through vocational training programs, they felt, would not be able to teach her what she was missing.

Sarah had visited numerous area schools that cater to young adults with high-school degrees who require direct lifeskills training. Her reaction to these programs clearly demonstrated how frustrated Sarah felt. Although she was aware that the programs could teach her what she needed to learn, she was unwilling to attend because the other students 'looked disabled.' She knew, using her social strengths, that she didn't fit in the world she lived

in, yet she desperately wanted to live solidly in it. Vocational programs looked at Sarah's low cognitive profile and offered her training for repetitive jobs that wouldn't allow her to use her gift of social interaction. Her mother said bluntly, with tears in her eyes, that those jobs would be the end of Sarah.

It was at this point that Sarah and I began working together. I quickly realized that my isolated speech-language skillbuilding sessions, despite their duration or frequency, would never be of the intensity or direct functional impact that Sarah needed. Sarah reported that she was thrilled at finally being taught at a level where she could actually learn. She did all her homework and frequently asked for more. But at the same time, in isolation, these skills were just grains of sand compared to the mountain of conceptual knowledge she lacked. It was as though the structure for inputting language had never become organized. Therefore, she missed out on learning not only in the speech-language



Kimberly Stewart, CCC-SLP speech-language pathologist

domain, but in life skills, in how her life and the world around her is structured. Though she took great pride in the perfection of her handwriting, I once witnessed her draw a house. She was unable to draw a triangle roof on the square base. I was shocked by how she must perceive the world around her, and I was concerned about her safety. With Sarah and her parents on board, we contacted occupational therapy and scheduled an evaluation. Tests were administered, therapy was recommended, and in order to best support this struggling adult, we quickly evolved into a team.

The team proved to be highly successful. We were able to validate the existence of the extreme discrepancy between Sarah's significant difficulty with everyday tasks and her strong social skills. Together we witnessed how effortlessly Sarah applied analytical thinking to social situations but how she struggled in all other environments, as though she fully understood the social schema but had absolutely no knowledge of other schemata in her world. For example, she had no concept that Boston is a city and that it is located in Massachusetts, a state. Once we shared our impressions of Sarah's profile, my colleague and I worked together toward devising a plan. We knew that our outpatient environment could not be a permanent place for Sarah to continue building her skills. Unfortunately, we also were acutely aware that there was nowhere else suitable for her.

We knew that the previously considered options of schools and vocational-training programs were not currently plausible, but neither was sending her away. We needed to figure out a way to boost Sarah's *continued on next page*

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self esteem, enable her to pursue her interest in child care, and help her to learn life skills. We had to get creative. We contacted the Back-Up Day Care Center at MGH and were welcomed.

Looking at Sarah's profile on paper, we should never have made this leap. Looking at Sarah as a person, our path was clear. With Sarah's permission, we explained our goals, expressed our concerns about her limitations and the impact on child care, and set up meetings. Sarah would be a regular volunteer with a schedule. The staff at the Center welcomed Sarah. They commented on her dedication to the position and her natural way with children who were magnetically drawn to her.

The first goal was met almost immediately: Sarah's self-esteem grew. She wore a photo badge on a strap around her neck like everyone else; she had a reason to get up in the morning; she was enjoyed for who she was; and, just as she had hoped, she went home at night tired with stories about her eventful day. As predicted, the children enjoyed Sarah, and Sarah enjoyed the children. She played with them, read to them, and quieted them for nap time. In our individual sessions, I taught her basic language concepts, and we discussed how these concepts applied to both her day care children and her adult life. So now, she was doing what she liked most and feeling good about it. Plus, she was repeatedly practicing the concepts she lacked in her disorganized approach to her environment: same/different, cause/effect, sequencing, predicting, and basic problem-solving. She was finally receiving sufficient practice in the fundamental structure of language that had passed her by during her toddler years, but she was doing it in a way that empowered her young-adult mind.

We spoke about the future—the tasks and level of responsibility

Sarah could handle; the most ideal and safe environment for her; the possible resources available for support; and what she needed in order to feel productive and contribute to society. We worked out a transition plan that integrated these needs. I met with Sarah's mother to devise a homebased learning program that would allow for Sarah to continue her volunteer work three mornings a week at the day-care center and spend the remainder of the day in structured academic sessions (geography,

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ynthia is a graduate of Boston University's Sargent School and has been a physical therapist for more than 25 years. Cindy's role as a 'float' physical therapist affords her the opportunity to work with different patient populations, on different units, with different staff members every day. Flexibility, insight, and experience drive her practice as she seizes the opportunity to share her knowledge with patients and staff alike.

Clinical Narrative

I have worked as a physical therapist for the past 28 years; the majority of my experience has been at MGH. I have held various positions, from staff therapist to supervisor. I've trained new staff, PT students, nurses, and residents. I have worked full-time, part-time, and per diem. Interestingly, my favorite role is staff therapist. In this role I'm able to do what I love most, work one-on-one with patients. The unique part of my job, my reward for being here so long (I joke), is that I am designated a float therapist. I infer from this job title, as I believe others do, that because I've been here so long, I must be able to 'do it all.' I'm called upon to practice in various settings and situations with patients of all ages and diagnoses. I have to say that most of the time I like the many challenges my job presents. Whether it's an unfamiliar diagnosis, a complex medical patient, or just a new unit where I don't know the staff or where equipment is kept -I must say, I'm never bored. The patient I've chosen for my narrative

highlights my diverse role and ability to use my professional and life experience in my work.

I am assigned for the day to the Med-Peds team. On my arrival, I overhear a discussion about who will take the new patient on Blake 13. I admit, I'm not sure what type of unit Blake 13 is, but I volunteer to take the case. I'm told it's the post-partum unit. I have no experience with post-partum patients or any type of birth problems that may arise. I can only relate because I am a mother myself. The fax I received reads: 34-year-old female with trouble walking. Thinking back, I remember I had trouble walking after the birth of my sons, too, but I didn't need physical therapy. There must be something more to this. My first step is to consult with one of our clinical specialists who has experience with postpartum patients and the possible neurological issues that may arise with labor and delivery. Armed with a brief overview of common birth complications that can cause difficulty walking, I forge ahead.

From the start, I encounter obstacles. The first is not knowing any of the nurses or physicians, the location of charts, the protocols for this unit, etc. I locate the appropriate people, introduce myself, and obtain all the information I think I'll need. I find the patient's name on a pink chart and start reading until the nurse kindly informs me that this is the baby's chart: the mothers' charts are gray.

'Mary' is a 34-yearold woman who has just had her first child, a boy. As I begin to look at her chart, I see a post-anesthesia note saying Mary has had no complications from the epidural along with a suggestion to consult Physical Therapy. I discuss the case in more detail with the nurse practitioner who is able to fill me in on some background information and answer some of my auestions. Of note, during Mary's labor she had an epidural and a long phase of pushing, about three hours. According to the notes in the chart and the nurse practitioner, she used a labor bar and may have been in a hip-and-knee flexed-



Cynthia Thibodeau, PT staff physical therapist

and-abducted position for some time. I begin to formulate my plan for evaluating this patient. I need to determine what her impairments are and determine the cause of these impairments so I can formulate an effective treatment plan and be able to discuss it with Mary, her husband, and other staff involved with her care.

The biggest obstacle I encounter on this unit is difficulty scheduling time with the patient. Evaluation and treatments have to be planned around rounds, visits from obstetricians, pediatricians, lactation consultants, breast-feeding, necessary bonding time, and emotional periods when Mary would frequently be in tears. The first day it takes four attempts before I'm able to do an initial evaluation. Over the next two days as I learn the way the unit works and get accustomed to Mary's schedule, I am much more

successful at scheduling treatment time. Mary and I quickly develop a good rapport and she works well with me despite her anxiety about these complications and trying to adjust to new motherhood.

On examination, I find that Mary has muscle weakness in her hip adductors, interior rotators, hip flexors, and quadriceps, left side greater than right. She also has some mildly decreased sensation over the anterior and medial area of her thighs, again, left side greater than right. I do not test her reflexes but a later neuro consult finds the patellar tendon reflexes to be diminished. I feel that her pain is likely due to her labor and delivery. The pain is localized to her perineal and vaginal areas with no radiation to either leg. There is notable improvement with ice, pain medication, and as her mobility increases over the

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three days I work with her. Her mobility, balance, and gait are impaired, requiring the use of a standard, and then a forward-wheeled, walker to help maximize her mobility and independence. We have some laughs about the fact that Mary feels like her grandmother and she reminds me I can't do much to improve her 'duck-walk' gait. She tells me she has walked this way all her life and is often kidded about it by her family. The gait pattern is worsened by her muscle weakness, which I assure her is temporary.

Through a review of the literature and in talking to one of our clinical specialists, I realize that my motor and sensory findings are consistent with a femoral and obturator nerve injury. This type of injury can be caused by the epidural, by a stretch or compression injury with the positioning of the mother, or by the pressure of the baby's head and body coming through the pelvis. With the information I obtain from Mary's chart, the literature review, and in talking to the anesthesiologist, it does not appear to be a complication of the epidural. I believe it is, in fact, a combination nervestretch/compression injury due to Mary's positioning during her prolonged pushing phase, with the epidural decreasing sensory cues to Mary that this injury was occurring.

I am able to reassure Mary and her husband that this complication is likely temporary and should resolve within several weeks. We discuss her discharge plans and the fact that she will need constant help with the baby initially due to her impaired mobility. We review and practice a written exercise program, how to go up and down stairs, and I obtain a forward-wheeled walker for her to take home. I also recommend continued physical therapy at home which she and her husband agree to. The plan is discussed with the case manager and with Mary's obstetrician as well.

Once again, my assignment has both challenged and rewarded me! I have had the opportunity to further expand my knowledge and experience. And I am rewarded by being able to calm some of this new mother's many valid *continued on page 12*

Staff physical therapist, Cynthia Thibodeau, PT, works with patient, Samuel Spencer, on White 6 following hip surgery.



ara is a graduate of the University of Delaware. She received her master's degree in Physical Therapy from the MGH Institute of Health Professions. Mara cares for patients with neurological disorders ranging from Parkinson's disease, to balance disorders, to the residual effects of head injuries. Mara works with physicians at the MEEI caring for patients with facial paralysis, which has required special study and research, including precepting with a national leader in the field.

Clinical Narrative

I have been a physical therapist for 15 years, the past seven years at MGH where I am a neurological clinical specialist. This is a multifaceted role where I provide direct patient care as well as clinical leadership to the physical therapy staff. Although my primary practice has been with adults who have movement disorders, I have had the unique opportunity to collaborate with a physician at the Massachusetts Eye and Ear Infirmary (MEEI) to initiate a rehabilitation program for people with facial paralysis. While this was a new patient population for me as a neurological clinical specialist specializing in movement control, this was a fortuitous union.

Movement of the facial muscles is anatomically related to balance control. This is best explained by describing the layout of the cranial nerves that originate in the brainstem. The eighth cranial nerve, responsible in part for balance, is next to the seventh cranial nerve, responsible for movement of the facial muscles. Certain diagnoses, for example

brain tumors, can affect both the seventh and eighth cranial nerves. In order to treat the whole patient, I expanded my knowledge base about what could be done for patients who had both balance disorders and facial paralysis. After reviewing the literature, I became familiar with the concept of neuromuscular re-training (NMR) to treat facial paralysis. Because this technique is innovative and appeared to require idiosyncratic patient interaction, I knew I needed to learn more about it. I needed handson experience. Interestingly, electrical stimulation, taught in physical therapy school, is no longer validated in the literature as an appropriate intervention. Without local resources. I contacted Jackie Diels, a renowned occupational therapist in Wisconsin, whose name recurred in the literature. After spending time with her in her clinic, I felt more prepared to embark on this collaborative relationship and provide skilled rehabilitation services to this patient population.

We can all remember the awkwardness of be-

ing a teenager. What we probably can't imagine is being a teenager with a brain tumor that causes limitations to seemingly basic motor skills such as walking, eating, and smiling. I think the following case illustrates my role as a physical therapist and how I learned the importance of integrating compassion, innovation, and the spirit of inquiry.

When 'Greg,' a handsome 14-year-old, first came to the Physical Therapy Department with his mother, he did not glance at me during the first 45 minutes of our hour-long appointment. Stemming from a diagnosis of a juvenile pilocytic astrocytoma (JPA) in 2001, Greg had a rather large tumor on his brainstem at the origin of the seventh and eighth cranial nerves. The tumor was resected in January of 2002, but post-operatively, his gait and balance were impaired. He had trouble walking and was unable to keep up with his peers at school. More alarming to Greg was the fact that the left side of his face was so severely paralyzed that he was unable



Mara Wernick Robinson, PT neurological clinical physical therapy specialist

to close his left eye, drink or eat without spilling, or smile. He was referred to me for 'facial physical therapy.'

Following the tumor resection, Greg had extensive rehabilitation at a nearby hospital. He was able to return to school, but his life was far from ordinary for a teenager. While in rehab, he learned how to walk again, but the left side of his face remained paralyzed. Because the left side of his face did not move normally, his parents recognized the need to look for other options to help him. This is what led them to Dr. Hadlock at MEEI. Dr. Hadlock suggested a very unique but promising surgery. She provided Greg with facial animation by performing a muscle transfer and nerve grafting procedure. The first procedure, the muscle transfer, involved moving the temporalis muscle (near the temples) and attaching it to the masseter (the biting muscles near the corner of the mouth). The goal is for the individual to learn to move his facial muscles, particularly the smile muscles, by biting down. The second surgical procedure was a nerve graft. The procedure, commonly called a 'twelve-seven,' involved taking the hypoglossal nerve, cranial nerve XII, and grafting it with the (damaged) facial nerve, cranial nerve VII. After surgery, the patient learns how to move his face by moving his tongue.

I began my initial evaluation of Greg by explaining to him what the next hour would entail. As part of the initial intake to determine the treatment plan, I asked him what his goals for physical therapy were. He looked away and shrugged. It was clear to me he was uncomfortable. His mom answered for him: "To move his face muscles again."

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Even though his gaze was directed toward the ground, I was able to examine his facial motion and muscle tone. I used a reliable and valid measuring tool, the Facial Grading Scale. He was unable to generate even a minor movement in his left facial muscles, and therefore unable to form a symmetrical smile, purse his lips, or close his left eye.

Very frequently, I teach patients with facial paralysis to use their muscles again by looking in a mirror. I could tell that Greg was not going to be comfortable looking in the mirror since he hadn't looked in a mirror since the tumor surgery.

"I don't want to know what I look like," Greg announced. "I don't really care what I look like."

To make matters more challenging for Greg, he wore an eye patch to compensate for diplopia, (double vision) another adverse result of the tumor excision. Because of Greg's shyness and the difficulty he had facing himself in the mirror, I chose not to have him do smile exercises in front of the mirror at home. Instead, I decided to build a firmer foundation in activating the muscle transfer to make the treatment easier for Greg. I suggested he chew as much sugarless gum as he could until our next meeting. (Chewing gum boosts muscle transfer.) I thought this was a small step in simplicity but a large step toward helping Greg regain muscle control and not erode his already battered selfimage.

My role as a physical therapist was to teach Greg how to move his face again. I knew I had the didactic skills to help Greg with his facial paralysis. However, after my initial meeting with him, I knew I had to find a way to connect with him as an individual, as a teenager. After reviewing the details of the muscle transfer and nerve grafting procedure, I turned on the television and watched my first episode of *The Simpsons*, thinking this is what most 14-year-olds were watching.

I started the second session by asking Greg how much gum he chewed over the past week. Did he get in trouble for chewing gum at school? So much for being cool. There was no eye contact. Searching for a way to break the ice, I casually mentioned that I had *continued on page 16*



Dage O



renda is a graduate of Salem State College and has spent her entire 13-year career at MGH working in critical care. For the past three years, Brenda has been a member of the critical care float team caring for patients in a variety of settings from the Burn Unit to the Cardiac Surgical Unit. She is the resource nurse in the Ellison 4 SICU, where, following the Rhode Island fire, she helped develop a resource manual on the unique care of burn patients for clinicians in the SICU.

Clinical Narrative

(This narrative has been edited for general publication)

I have been a critical care nurse for 13 years, the last three years as the resource nurse in the Ellison 4 Surgical Intensive Care Unit. Although I have seen hundreds of patients throughout my professional career, there are a few that will always stand out in my mind. I remember these patients because I know my involvement in their care made a significant difference in their outcome, however big or small.

One such case occurred this past September when I was approached by a SICU nurse about a patient who required assistance in communicating her wishes regarding end-of-life decisions.

Mrs. B was a 62-yearold woman who'd had a stroke 12 years before that resulted in a leftsided hemiparesis. I met Mrs. B shortly after she arrived on the unit after undergoing a thoracoabdominal aneurysm repair. She had suffered additional complications from this surgery including loss of movement of her right leg and probable paralyzation of her diaphragm. I knew that a difficult road lay ahead for both Mrs. B and her family. Mrs. B's family were her strongest allies, and she was going to need their support to get through the next couple of months. Despite Mrs. B's condition, her spirit was unparalleled by her will to live.

In the weeks that followed, the SICU team made many attempts to extubate Mrs. B with little success. She would rally for a few days but ultimately require intubation again. The team finally rehabilitated her sufficiently to maintain her extubation for more than a few days and was ready to transfer her to a unit. She had finally graduated! However, the following week I received a call that Mrs. B was in respiratory distress and needed to return to the SICU. She was reintubated and transferred back. The SICU team discovered that Mrs. B did indeed have a paralyzed diaphragm. I knew at this point that Mrs. B would eventually need a tracheotomy. This meant that rehabilitation in a rehab hospital was probable, thereby delaying her return home.

After a few days in the SICU, we were able to extubate Mrs. B again, and she looked better than she ever had. She was lucid, conversant, and participating in her own care with ease. This was in sharp contrast to her abilities prior to leaving the ICU.

At this point, Mrs. B's surgeon approached her to discuss the probability of a tracheotomy. He asked her to consider the number of times she had been re-intubated, how de-conditioned she had become, and the complication of her paralyzed diaphragm.

Mrs. B and her husband felt very strongly that she did not want a tracheotomy. She voiced her concerns about the procedure being a permanent measure as opposed to a temporary one. Mrs. B seemed most upset about the additional care that would be required by her family members should the tracheotomy be performed. The surgeon asked her not to get ahead of herself and suggested Mrs. B take a 'wait and see'



Brenda Whelan, RN critical care resourse nurse, Ellison 4 Surgical Intensive Care Unit

outlook. He stressed that he could not make any promises regarding the permanency of the tracheotomy.

Mrs. B said, "If I choose not to wake up tomorrow, that's my decision to make."

Mrs. B told her nurse the decision was hers. but she and her husband worried that her wishes might not be carried out. The nurse caring for Mrs. B had witnessed a number of interactions between the patient and the clinical staff and thought that help was needed. It was at this time that the nurse caring for Mrs. B pulled me aside to discuss the conversation that had taken place and request my assistance. It was important to me to do everything possible to restore this family's faith in their healthcare team.

One member of the team discussed with me his discomfort with Mrs. B's decision. Another felt that Mrs. B was somehow confused and didn't really know what she was talking about. Another felt he would be able to 'convince' Mrs. B when he spoke with her the next day.

This was of concern to me as well as to the nurse who had been at Mrs. B's bedside during the initial interaction. I felt I needed to take action. I encouraged Mrs. B's nurse to ask the anesthesia attending to meet with Mrs. B to assure her that her wishes would be carried out. I went to my nurse manager and she suggested we call the Office of Patient Advocacv.

In the meantime, I had a discussion with one of the team members about his feelings regarding the patient's decision. I asked him to consider Mrs. B's feelings at having to make such a difficult decision. I expressed my opinion that it's just as important to offer advice as it is to *continued on next page*

Vlage 10 -----

allow the patient the right to make an informed decision. As Mrs. B's healthcare providers we needed to be attentive to her concerns and consider her point of view.

I encouraged the anesthesia attending and Mrs. B's bedside nurse to have a discussion with Mrs. B and her family about considering DNR/ DNI status. The anesthesia attending spent a considerable amount of time with Mrs. B and her family in a series of discussions, each time allowing them ample opportunity to process the information. Ultimately, Mrs. B and her family decided together that she should request a DNR/ DNI order.

A representative from the Office of Patient Advocacy spoke with Mrs. B and her family. The representative suggested that Mrs. B's competency be established so that her family could carry out her directives in the event that she became unable to do so herself.

I have seen families struggle with these decisions before. Every patient and family is unique. It takes a very strong patient and a cohesive family to be able to come to decisions like those made by Mrs. B and her family. I applaud this family and the healthcare team for turning a negative situation into a positive one with constructive give-and-take and attentive listening. I came away from this situation with renewed faith in the healthcare team.

It was Friday, and I was leaving for the weekend. I felt secure in the knowledge that I had done my best to help allow Mrs. B and her family to make a very difficult decision. And in the process, we successfully restored this patient's faith in the healthcare system.

I returned on Monday to learn that Mrs. B's condition had declined and she was going to require intubation once again. Much to my surprise, I also learned that Mrs. B and her family had decided to rescind the DNR/DNI order. The surgeon came by and the family discussed their change of heart. The surgeon had come to realize the depth of personal struggle this family had been through and he wanted them to take the time they needed to come to the right decision for them.

The team was once again successful in getcontinued on page 13



Award Ceremony

continued from front cover

excellence include:

- having a bias for action that is hands-on and value-driven (advocating for what is important)
- staying close to the customer; taking the time to learn their preferences and how to meet them
- being autonomous and entrepreneurial; going

above and beyond to accomplish what needs to be done

- sticking to the knitting; designing processes that enhance the patient experience
 teamwork; it takes a
- village to provide seamless, coordinated care Said Ives Erickson,

"Keep these principles in mind as we meet this year's recipients. You will see how these prin-

ciples live in the practice

of each clinician we are honoring today."

Before presenting the awards, Ives Erickson invited speech-language pathologist, Kimberly Stewart, to read her narrative aloud (see page 4). Following the reading, Carmen Vega-Barachowitz, CCC-SLP, director of Speech-Language Pathology, engaged Steward in a dialogue about the principles that drive her practice and the elements of decisionmaking that led to her powerful narrative.

Introducing the recipients one at a time, Ives Erickson read from their letters of support. Nancy Caruso, RN, who works with Erica Edwards, wrote, "Erica is a rock in the ever-changing environment of the Coronary Care Unit. With her extensive knowledge and experience, she consistently provides compassionate, intelligent, and professional care to patients and families. She inspires confidence and trust, relieving the anxieties that are always present in the CCU."

Robin Mirante, CCC-SLP, speech-language pathologist and colleague of Kim Stewart, wrote, "In a very short time I learned that Kim possesses the most important combination of

continued from page 7

talents. These talents include her superior clinical skills, her keen ability to perceive and respond to patients at their precise level of need, and her innate compassion and willingness to strive to reach the optimal outcome for patients in her care regardless of the extra effort involved in doing so... She deftly makes the technique and art of being a superior clinician appear simple, in a manner similar to a professional dancer who is able to make complicated and physically challenging performances appear simple to the observer."

Nancy Goode, PT, Physical Therapy clinical services coordinator, wrote of Cindy Thibodeau, "Cindy's ability to pull together many loose ends in one encounter to *continued on next page*

Past Macaluso Recipients

First award—September 5, 1996 Stephanie Macaluso, RN

July 2, 1998 May Cadigan, RN Pat English, RRT Valerie Fullum, LICSW Sarah Rozehnal Ward, CCC/ SLP

- December 17, 1998 Maureen Beaulieu, RN Tessa Goldsmith, CCC/SLP Diana Grobman, RN Karen Lechner, LICSW Donna Slicis, RN
- July 1, 1999 Rochelle Butler, LPN Alice Chaput, RN Diane Plante, PT Louise Sethmann, RN
- January 6, 2000 Elizabeth Johnson, RN Sucheta Kamath, CCC/SLP Sandra McLaughlin, LICSW Fredda Zuckerman, LICSW

June 15, 2000 Emilyn S. Bellavia, RN Mary Elizabeth McAuley, RN Diane McKenna-Yasek, RN Marica Wasenius Rie, PT

> December 12, 2002 Kathryn Best, RN Jennifer Kelliher, RN Michael McElhinny, MDiv Carol McSheffrey, LICSW Jean O'Toole, PT

December 7, 2000 Gae Burchill, OTR/L Pamela DiMack, RN Claire Farrell, RN Marie Elena Gioiella, LICSW Irene Giorgetti, RN Lisa Sohl, RN Susan Thel. MSW

June 21, 2001 Neila Altobelli, RRT Constance Dahlin, RN Sylvia Gordon, LICSW Catherine O'Malley, RN

December 13, 2001 Clare Beck, RN Anita Carew, RN Robert Goulet, RRT Kristen Jacobsen, SLP Thomas Lynch, RN

June 13, 2002 Sharon Brackett, RN Marguerite Hamel-Nardozzi, LICSW Mary Lou Kelleher, RN Judith Lynch, RN Kristin Parlman, PT Debra Smith, RN anxieties and even make an her laugh while we both ex work hard to be sure she ble is ready to safely head tea home with her husband ne and new son.

Exemplar (Thibodeau)

Comments by Jeanette Ives Erickson, RN, MS, senior vice president for Patient Care and chief nurse

It's evident that Cindy loves her work and the diversity of practice that comes with being a 'float' therapist. This narrative speaks to the positive outcomes that can occur when the skill and knowledge of an experienced clinician are blended with a spirit of teamwork and a willingness to always learn more.

A relative stranger to Blake 13, Cindy quickly accessed important resources, consulted the literature, and spoke with other clinical specialists to validate her findings. Then she worked closely with Mary and her new family to ensure a safe and speedy discharge. What a wonderful story.

Thank-you, Cindy.

The Ceremony

continued from page 12

ensure her patients' care is comprehensive and seamless is only one of her many strengths. Despite the chaos of the busy inpatient environment, Cindy is able to focus in the moment and connect with her patients and their families. She goes above and beyond to meet their needs, achieve the best possible outcomes, and ensure their experience at MGH is a positive one."

Barbara Moscowitz, LICSW, social worker, said of Mara Wernick Robinson, "In my twenty-five-year career at MGH I've been privileged to work with the very best clinicians—there's no doubt that Mara is in the company of those rare professionals. She is able to appreciate the importance of all levels of interventions and evaluate patients in the critical context of their social and physical environment. Mara treats each patient with heartfelt respect and appreciation for their chal-

lenges."

Robert Goulet, RRT, respiratory therapist and former Macaluso award recipient, said of Brenda Whelan, "Very early in her career Brenda demonstrated the analytical ability to manage hemodynamically complex patients. In a crisis atmosphere, she is logical, decisive, and if necessary, forceful in effecting the proper care for her patients. I've witnessed her leading the SICU team in the proper management of patients in hemodynamic crisis... She never loses sight of

the dignity of the individual or her responsibility as the primary caretaker of that individual."

In each recipient's acceptance remarks the themes of teamwork, advocacy, leadership, innovation, and family support came shining through. Ives Erickson thanked members of the Macaluso Review Board for their work in selecting this year's recipients. She closed by saying, "I know Stephanie Macaluso would be proud. I know she is smiling on us today as we bestow this honor in her memory. I thank Erica, Kim, Cynthia, Mara, Brenda, and all MGH employees for everything you do to make this hospital the greatest hospital in the world. Excellence in patient care is alive and well at MGH."

Exemplar (Whelan)

continued from page 11

ting Mrs. B stabilized, and she was sent back to the unit without a DNR/ DNI in place.

I have since learned that Mrs. B had a tracheotomy placed. The complexities of this situation remind me that human life is a process, and there are no easy answers. I am often reminded, especially in situations like this, that my work includes providing information and support to patients in the best way I can, thereby allowing my patients to make informed decisions. I came away from this experience feeling proud to have been part of a caring team of healthcare providers and of this patient's struggle to understand the complexities that were facing her. **Comments by Jeanette Ives Erickson, RN, MS, senior vice president** for Patient Care and chief nurse

Throughout this narrative it's clear that Brenda's priority was to do what was best for Mrs. B and her family while at the same time listening to her colleagues. Caregivers may not always agree with the decisions their patients make, but through Brenda's advocacy, the team came to understand and respect Mrs. B's wishes.

This is an important narrative and one that probably wasn't easy to write—just as it's not easy to be one voice against a majority. But when it comes to patient care, doing what's right is more important than doing what's easy.

Thank-you, Brenda.

Exemplar (Stewart)

continued from page 5

math, early child-care background) and lifeskills sessions (planning for meals, housekeeping, budgeting, and planning her time). For this, Sarah would be 'paid' by her mother, who would deposit a livable sum into a bank account. Sarah's mother had seen a need for this involvement for years and willingly offered the time. Sarah, knowing the structured environment and enjoying the scope of a work day, was willing to give it a try.

Each patient who walks through the door can be said to fit a profile, a cluster of symptoms. But just as strong as that standard profile of strengths and weaknesses is how individuals work to adapt and how willing they are to continue to strive. Many adults with developmental learning disabilities have worked alone for years to compensate for their difficulties. Their life experiences and attempts to address or avoid situations alter their thought patterns to such a degree that test scores alone can no longer guide practice. Sarah, with her ability to interact with savvy in a

waiting room in the middle of a city she doesn't know, in a state she doesn't know is a state, keeps me looking beyond that cluster of symptoms to the potential in every patient.

Comments by Jeanette Ives Erickson, RN, MS, senior vice president for Patient Care and chief nurse

We may not think of speech-language pathologists as clinicians who typically save lives, but that's exactly what Kim did. Kim hadn't known Sarah for very long, but she knew Sarah's mother was right when she said a job that didn't allow Sarah to use her creative or social skills would 'be the end of her.'

Kim looked beyond the statistical profile to the person. She helped build Sarah's confidence and sense of self worth. Kim reached out to other members of the team and other members of the MGH community, and found a position where Sarah could feel needed and fulfilled; a position where Sarah could feel tired at the end of the day. What a wonderful narrative.

Thank-you, Kim.

Educational Offerings available on-line

The Center for Clinical & Professional Development lists educational offerings on-line at: http://pcs.mgh.harvard.edu

For more information, or to register for any program, call the Center at 6-3111.

Macaluso Moments

Patient Care Services recognizes clinicians with 11th presentation of the Stephanie M. Macaluso, RN, Excellence in Clinical Practice Awards









Excellence: something that is exceptionally good; superior; worthy of distinction, greatness, or exaltation; perfection

Continued on next page

January 8, 2004

The Stephanie M. Macaluso Excellence in Clinical Practice Award recognizes direct-care providers whose practice exemplifies the application of values put forth in our vision: practice that is caring, innovative, guided by knowledge, built on a spirit of inquiry, and based on a foundation of leadership and entrepreneurial teamwork



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Exemplar (Wernick-Robinson)

continued from page 9

watched The Simpsons, and he responded with a line from the show. We chatted about Bart and Marge and Homer for a little while. Having established a bit of camaraderie with Greg, I tried to introduce the concept of looking in the mirror. I knew I needed to understand his personal reticence but I also needed to be direct with our goals for physical therapy. With a little parental prodding from his mom, we nudged Greg forward with his willingness to have a positive outlook on his PT goals. From there, I asked him if it would be all right if we looked at his face together. I brought the mirror into our private treatment room.

At first glance, he said, "This is what I look like?" I then showed him that by biting down, he could move his muscles to form a small smile (the outcome of the muscle transfer); and that by moving his tongue he could also move his facial muscles (the outcome of the XII-VII transfer). He thought these 'tricks' were really cool. Another small breakthrough with a teen! He seemed to understand that these exercises could help, and he agreed to do facial exercises in front of the mirror at home at least once per day.

On his third visit, Greg said he hadn't done the exercises at home. He

didn't like looking at himself in the mirror. I now had two challenges. Motor control improves first with visual biofeedback from a mirror. And the exercises needed to be completed daily to build muscle memory. How do I make this work for a self-conscious teenager? First, we spent time doing the exercises together with and without the mirror. He discovered that after a few repetitions with the mirror, he was able to 'remember' how to move his smile muscles without the mirror. We agreed that he would do his exercises while watching television, by using a small hand mirror (during commercials) and then doing the exercises without the mirror. Luckily, The Simpsons are in

syndication! In subsequent visits, Greg and I got to know each other better. He said he looked forward to coming to physical therapy, and often came in alone while his mom waited outside. He was not the same young man I had met two months earlier. As Greg became more confident, his smile became brighter and more symmetrical. He was able to eat in the school cafeteria and go out with his family to restaurants without spilling his food or beverage out of the corner of his mouth. Even though he didn't do all his exercises in front of a mirror, he did them, and made improvements in the motor control of his face.

Greg's insurance plan allowed him to have eight visits in sixty days. But given the complexity of the case and the long process of nerve regeneration, I requested an exception to the sixtyday rule to maximize his outcome; and my request was approved.

Despite the gradual nature of nerve recovery and the need for repeated trips to MGH, Greg remained motivated to do his home exercise program. Each week, there were small changes in the motor control of his facial muscles. After six months, he had made substantial gains. Greg reached the functional goal of generating a smile, blowing out candles for his 15th birthday, and closing his eye completely. Through my collaboration with my colleagues at MEEI, I have not only expanded my scope of knowledge to include evaluation and treatment of patients with facial paralysis, but I have gained an appreciation for this complicated diagnosis and the implications of the impairments associated with it.

I started this story with the goal of describing Greg's ability to overcome far more than the awkwardness of adolescence. I also wanted to relay that I found my role as a physical therapist to be rewarding, knowing I was able to help him smile in front of a mirror again. It was a privilege to work with Greg and his parents and witness their commitment to helping him battle this unfortunate diagnosis. This narrative is dedicated to the new challenge Greg and his family face with the recent news that the tumor has grown back.

Comments by Jeanette Ives Erickson, RN, MS, senior vice president for Patient Care and chief nurse

Can you imagine the self-esteem issues for a teenager who's unable to smile or control his facial movements due to facial paralysis? Mara went 'outside the box' to come up with a way to forge a relationship with Greg. Who ever would have guessed that *The Simpsons* would fulfill a therapeutic need?

But Mara went further—she provided a safe and supportive atmosphere for Greg to look in the mirror for the first time. She negotiated an exercise regimen that Greg could comply with. At every stage of Greg's treatment, Mara was creative, compassionate, and tenacious. I'm sure it is a comfort to Greg and his family to know that clinicians like Mara will be there during the challenges that lie ahead.

Thank-you, Mara.

Share your practice Share your knowledge Write an exemplar for Caring Headlines

The Yvonne L. Munn Nursing Research Award

The Center for Clinical & Professional Development is now accepting proposals for The Yvonne L. Munn Nursing Research Award.

Proposals must be received by February 15, 2004, in order to be eligible for the 2004 award.

Recipients receive a \$1,500 grant to fund their research studies.

Eligibility requirements and guidelines for proposal development are available in The Center for Clinical & Professional Development on Founders 6.

For more information, contact Brian French at 4-7842.

January 8, 2004



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When/Where	Description	Contact Hours
January 20 8:00am-4:00pm	Intermediate Respiratory Care Respiratory Care Conference Room, Ellison 401	TBA
January 21 7:30am–12:30pm	Pediatric Advanced Life Support (PALS) Re-Certification Program VBK 601-607	
January 22 1:30–2:30pm	Nursing Grand Rounds O'Keeffe Auditorium	1.2
January 23 8:00am-4:30pm	Legal Issues Facing Clinicians O'Keeffe Auditorium	TBA
January 26 and 27 7:30am-4:30pm	Intra-Aortic Balloon Pump Workshop Day 1: BWH; Day 2: VBK601	14.4 for completing both days
January 27 8:00am and 12:00pm (Adult) 10:00am and 2:00pm (Pediatric)	CPR—Age-Specific Mannequin Demonstration of BLS Skills VBK 401 (No BLS card given)	
January 28 8:00am-2:30pm	New Graduate Nurse Development Seminar II Training Department, Charles River Plaza	5.4 (for mentors only)
February 3 8:00am–2:00pm	BLS Certification for Healthcare Providers VBK601	
February 5 7:30–11:00am/12:00–3:30pm	CPR—American Heart Association BLS Re-Certification VBK 401	
February 5 8:00am–4:30pm	Workforce Dynamics: Skills for Success Training Department, Charles River Plaza	TBA
February 6 8:00am–4:30pm	Wound Skin Care Update: 2004 O'Keeffe Auditorium	TBA
February 9 7:30–11:00am/12:00–3:30pm	CPR—American Heart Association BLS Re-Certification VBK 401	
February 9 8:00am–4:00pm	Advanced Cardiac Life Support—Instructor Training Course O'Keeffe Auditorium. Current ACLS certification required. Fee: \$160 for Partners employees; \$200 for all others. For more information, call Barbara Wagner at 726-3905.	
February 10 8:00am and 12:00pm (Adult) 10:00am and 2:00pm (Pediatric)	CPR—Age-Specific Mannequin Demonstration of BLS Skills VBK 401 (No BLS card given)	
February 11 8:00am–2:30pm	New Graduate Nurse Development Seminar I Training Department, Charles River Plaza	6.0 (for mentors only)
February 11 1:30–2:30pm	OA/PCA/USA Connections Bigelow 4 Amphitheater	
February 11 8:00–11:30am	Intermediate Arrhythmias Haber Conference Room	3.9
February 11 12:15–4:30pm	Pacing: Advanced Concepts Haber Conference Room	4.5
February 11 11:00am–12:00pm	Nursing Grand Rounds Sweet Conference Room GRB 432	1.2
February 12 8:00am–4:30pm	Building Relationships in the Diverse Hospital Community: Understanding Our Patients, Ourselves, and Each Other Training Department, Charles River Plaza	7.2

For detailed information about educational offerings, visit our web calendar at http://pcs.mgh.harvard.edu. To register, call (617)726-3111. For information about Risk Management Foundation programs, check the Internet at http://www.hrm.harvard.edu.

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Peace on earth, good will toward all. Happy holidays from Patient Care Services





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History and background of the Stephanie M. Macaluso, RN, Excellence in Clinical Practice Award

n August of 1996, Jeanette Ives Erickson, RN, senior vice president for Patient Care, formally announced the creation of the Excellence in Clinical Practice Award (originally called the Expertise in Clinical Practice Award). The purpose of the award is to recognize direct-care providers whose practice exemplifies the expert application of values put forth in our vision: practice that is caring, innovative, guided by knowledge, built on a spirit of inquiry, and based on a foundation of leadership and entrepreneurial teamwork.

The first recipient of the award, in 1996, was Stephanie M. Macaluso, RN, thoracic clinical nurse specialist. In honor of the high standards she set as an expert caregiver, the award is now known as the Stephanie M. Macaluso, RN, Excellence in Clinical Practice Award. Macaluso embodied the qualities and characteristics of an expert practitioner. She was known for her strong knowledge base and intuitive skills. She knew when a clinical situation was changing even when common indicators remained unchanged. As an expert coach, she was one on whom peers relied and to whom physicians responded immediately because of her solid, proven track record of sound judgement.

Macaluso did not stand outside of a patient's realm of experience in her role as clinical teacher. She stood alongside patients conveying empathy and genuine concern. Macaluso's ability to be with patients in a way that acknowledged their shared humanity is the basis of a caring practice.

Macaluso understood the relationship of health, illness and disease. It was this understanding that led her in her caring work to seek patients' stories. She knew that every illness had a story—relationships were disturbed, plans were thwarted, and symptoms became laden with meaning as to what else was going on in a patient's life.

Macaluso had the uncanny ability to put herself in touch with others and bring the encounter to an intimate level. It's hard to express how she made this contact with patients; maybe it was the way she approached them, the questions she asked, or the language she used. But somehow, they trusted that she knew what she was talking about. This trust and understanding allowed her to connect with patients and promote a sense of caring.

Macaluso had a keen ability to nurture staff and enlist them in her love of patient care. She epitomized the essence of what nursing is truly about.

We continue to celebrate expert practice throughout Patient Care Services. The Stephanie M. Macaluso, RN, Excellence in Clinical Practice Award is now given annually. Registered nurses, occupational therapists, respiratory therapists, physical therapists, speechlanguage pathologists, social workers and chaplains who provide direct care are eligible for the award and may nominate coworkers whose practice exemplifies the standards described earlier.

Clinicians who are nominated submit a professional portfolio which is reviewed by a selection committee comprised of clinicians, administrators and MGH volunteers. To assist recipients in achieving both personal and professional development, recipients receive tuition and travel expenses to the professional development conference of their choice.

The Stephanie M. Macaluso, RN, Excellence in Clinical Practice Award allows us to publicly re-commit ourselves to the highest standards of care we hold for our patients, and contribute to the on-going professional development of clinicians within Patient Care Services.

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