HEALTH ADVOCACY BULLETIN

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Really Caring: Why a Comprehensive Healthcare System Includes the Arts

by Susan Perlstein, M.S.W.

[Editors' Note: the following is excerpted from an article in High Performance*, and is reprinted by permission from the author]*

You can gauge the humanity of a society by the way it treats its young and old, to paraphrase a familiar quote from Dostoyevsky. Holding the U.S. healthcare system to this yardstick, it's clear we're not very humane. For example, the healthcare system for an aging population in New York City provides senior centers for well elders, adult day healthcare centers for those still mobile, nursing homes for the frail, hospital and hospices for the sick and dying. But most of these institutions treat aging as a disease rather than a natural process. They emphasize a medical rather than a social approach, often reducing people to their medical "condition." Diseases are treated, not human beings.

A system that really cares for people should sustain their well-being in their communities, and provide a continuum of care from birth to death. This social model uses each person's individual strengths and integrates him or her into a support system that provides for emotional as well as physical needs. Arts programs can do this by tapping into all aspects of a person's well-being. Thus, a comprehensive healthcare system includes the arts.

To some extent, creative arts therapies, arts programs and arts organizations are already part of the picture in the current healthcare system. But there is room for much more as society stands at the crossroads, hopefully moving toward a more holistic understanding of health care.

How can arts programs contribute to healthcare and well being? As director of Elders Share the Arts (ESTA), a community-based arts organization primarily serving elders, in and out of institutions, and their communities , I am in a unique position to observe and to think about health care needs across the life span. ESTA designs and conducts arts programs that address some of the needs of old and young in their communities through what we call the Living History arts -- movement, theater, music, writing and the visual arts. ESTA teaching artists work in senior centers, nursing homes, hospitals and schools. I know from this experience that the arts are an essential component of individual well-being and community empowerment.

When considering the role of the arts in healthcare, we must first take into account the political climate we live in. Those of us who work in underserved neighborhoods clearly see and feel the debilitating effects of the recent federal, state and city cuts to healthcare, education and welfare in New York City. These mean-spirited cuts affect all those who take part in our programs: participants, families and friends, as well as administrators and staff in the institutions that provide social and educational opportunities. But I know the arts can reconnect people, even in this barebones economy.

Second, we must realize that American culture is a youth culture that prizes mobility, invention and technology. What is the latest thing? Do you have it?

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From The Editors:

Medical care as it has come to be practiced in our health care centers today has become for many a very solitary, impersonal experience. Patients find themselves in sterile environments surrounded by, and hooked up to, the fruits of this century's technological advances. The last few decades has seen a shift, however, as patients and providers have looked for ways to break through this sense of isolation. Alternative therapies, most often today referred to as allied or complementary therapies, have found their way back, as patients have sought to regain control over their own bodies and their own care. There is also a growing sense that practitioners of "traditional" Western medicine are becoming more and more receptive to, and beginning to recognize the benefits of, this new direction. The change of name itself from alternative to complementary reflects a change of climate and a recognition that it is no longer a case of either/or.

This issue of the Bulletin attempts to provide information on some of the non-medical alternatives available to help patients address quality of life issues through modalities that provide comfort, relaxation, connection, peacefulness. We feel that as advocates in the field of health care, we should be aware of and versed in this growing development. Many thanks to those who have contributed their time and expertise to making this issue possible.

Congratulations to the four December 1998 graduates - Lisa Salandra-Birnbaum, Patricia Saunders, Eleanor Scarcella, and Sherisse Webb - who will be profiled in the Spring issue of the Bulletin.

SPECIAL NOTE

We wish to extend a very warm welcome to Marsha Hurst as the new Director of the Health Advocacy Program at Sarah Lawrence College. We feel confident that Dr. Hurst, who has been a member of the faculty of the Health Advocacy Program for the last thirteen years, will meet the challenges of her new position with caring, commitment and insight. We look forward to working closely with her as she continues to shape the program to address the continuous changes that characterize the health care system today.

— Irene Selver and Karen Martinac

http://www.slc.edu/pages/h/health

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ADVOCACY ONLINE

Society for the Arts in Healthcare
www.societyartshealthcare.org

American Holistic Health Association
http://ahha.org

American Holistic Nurses Association
www.ahna.org

Families USA Foundation:
"The Voice for Health Care Consumers"
www.familiesusa.org

HealthWorld Online
www.healthy. net

Assistance Dogs International
www.assistance-dogs-intl.org

International Association of Assistance Dog Partners
www.iaadp.org

Canine Companions for Independence
www.caninecompanions.org

Delta Society
www.deltasociety.org

Animal Assisted Therapy Team
www.aat.org

American Music Therapy Association
www.musictherapy.org

Songs of Love Foundation
"Dedicated to creating personalized songs for chronically and terminally ill children and young adults." www.songsoflove.org

Songs for Healing: The Open Ear Center
www.openearjournal.com

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Where can I get it? In such a culture, elders have little value. There is small regard for wisdom and historical connection, and almost no recognition that one generation builds on the achievements of those before it.

Yet, a significant demographic transformation is in process - America is aging. By the year 2030, 28 percent of the population will be over 60, and the number of those over 85 will triple. There will be nearly twice as many older adults in 2030 (70 million) as there are today (32 million). Americans are living longer lives than ever before. This population revolution presents an extraordinary opportunity and challenge for arts organizations, artists and the healthcare system.

> *"Arts programs tap into all aspects of a person's well-being."*

THE ARTS CONNECTION

As I watch people move through our arts programs, learning new skills, discovering new parts of themselves, finding creative ways of expressing their perceptions, I have no doubt about it - art heals. The arts provide preventive and integrative approaches to healthcare, building self-esteem and a sense of identity and belonging, connecting people and celebrating life. All these things are part of an individual's healing process.

Group arts activities bring people together on common ground, and can bring healing to a community. Time and again in ESTA's programs, I have seen people learn to observe, explore and create together. We lead them to explore commonalities and differences, essential building blocks of respect, tolerance, appreciation and enjoyment of each other.

When we connect ages and cultures, it's obvious the arts are a tool for social change, in and out of institutions. Incorporate community-building arts projects into the healthcare system and they can't help but change the nature of the relationships in surprising, ongoing ways Our collaboration - murals, plays, music, dance and writing projects -often bring unlikely partners to the table. Once they are working creatively together, they give themselves permission to stretch their imaginations toward critical thinking, decision-making, problem-solving.

ESTA's cross-generational festivals are a real celebration of cultural diversity, bringing our community performing-arts groups together to create ceremonies that recognize the special place of each generation. The festival is a place where they can come together to see, discuss, share, question and appreciate each other. You can literally see the connection being made as exploration and creativity deepen caring community relationships.

Inside institutions, arts projects can help to stabilize communities experiencing the tension around difference that results in disrespect, violence and burn-out. Arts programs can create positive, invigorating, life-giving and life-sustaining activities that, again, make those human connections. In a caring, connected community, people are more likely to stay healthy because they look out for each other.

THE ESTA MODELS

ESTA has two very useful programs called Legacy Works that help to close the gap in the continuum of healthcare by identifying community needs. One is an intergenerational homebound program in Manhattan's East Harlem (El Barrio), the other is a program at a long-term care facility, St. Alban's V.A. Hospital in Queens.

> *"...I know the arts can reconnect people, even in this bare-bones economy..."*

The problems that confront each community are different. The East Harlem neighborhood lacks resources and connections to coordinate the healthcare system. At St. Alban's everyone is under one roof, but the medical hierarchy determines the quality of life, and people are defined by their illness. In both cases, people want more control over their lives and are looking for supportive human relationships.

To give you an overview of the full scope of our arts activities, ESTA is the only comprehensive resource center on arts for the aging in New York City and, as far as we can determine, in the nation. We believe the vital key to improving the scope and quality of creative arts programs for elders and their communities is the linking of generations and cultures. One of our most creative, therapeutic and empowering tools for working with elders and intergenerational groups has been the life review process.

In this process, ESTA's staff of professional artists conducts workshops in storytelling and interviewing skills, enabling participants to integrate past experiences into their present lives. They then transform these experiences into an art form: theatre, dance, music, writing or visual art.

We conduct 20 such Living History programs in New York City, directly serving about 1,000 older adults and young people each year. Each program year culminates in a series of Living History festivals that celebrate their wisdom, vitality and cultural legacy by presenting their creative work at community centers, senior centers, schools, museums, nursing homes and hospitals.

These activities have sparked many senior arts coalitions, like Pearls of Wisdom, a group of older storytellers, and a traveling exhibit of work by older visual artists called "Discoveries." We also train artists, educators and healthcare professionals to create ESTA model programs, reaching more than 15,000 people each year.

Legacy Works, our visual arts program, aims at creating artworks by integrating the stories from an elder's life.

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HOLISTIC is an Adjective ... Not a Noun

From an article by Suzan Walter, President, American Holistic Health Association

Are you confused about the meaning of holistic? Have you ever been discussing holistic health and discovered that the other person was defining holistic in a totally different way than you? This is not surprising, since there are no accepted standard definitions for holistic, holistic health, or holistic medicine. Most usage falls within two common definitions:

- Holistic as a whole made up of interdependent parts. You are most likely to hear these parts referred to as 1) the mind/ body connection, 2) mind/ body/ spirit, or 3) physical mental emotional spiritual aspects. When this meaning is applied to illness, it is called *holistic medicine* and includes a number of factors, such as 1) dealing with the root cause of an illness, 2) increasing patient involvement, and 3) considering both conventional (allopathic) and complementary (alternative) therapies.

- Holistic as a synonym for alternative therapies. By this definition, "going holistic" means turning away from any conventional medical options and using alternative treatment exclusively. This meaning mainly relates to illness situations, and sometimes is used for controversial therapies.

The expanded perspective of holistic as considering the whole person and the whole situation allows us to apply holistic as an adjective to anything. For example, we can develop a new project at work or re-organize our life holistically. When illness is involved, the broad definition of holistic allows us to integrate both conventional and complementary therapies. Consider adopting this holistic approach to your life.

AHHA's holistic approach

The American Holistic Health Association (AHHA) promotes holistic health as an approach to creating wellness which encourages you to:

- Balance and integrate your physical, mental, emotional and spiritual aspects
- Establish respectful, cooperative relationships with others and the environment
- Make wellness-oriented lifestyle choices
- Actively participate in your health decisions and healing process.

You are invited to peruse the other information in the AHHA section on the Internet and explore incorporating this holistic approach into your life.

Suzan Walter, M.B.A., is co-founder and current president of the American Holistic Health Association, and past president of the American Holistic Medical Association. She is the creator and director of the Global Health Calendar on the Internet Health World Online (http://www.healthy.net), and facilitates networking for speakers, practitioners and healthcare associates within this web site.

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With our help, older people can transform their memories into Life Books, collages and tape stories to pass on to relatives and friends. If intergenerational, this activity can also bring communities together by creating lasting personal relationships between young and old.

CONCLUSION

At a time when instability, loss and isolation threaten the quality of life, older adults need meaningful activities to help them pass on values and history that can connect generations. Art making can make a great difference. Art programs like Legacy Works make partnerships both in the community and in the institution that help to fundamentally change the nature of human relationships. Through programs like these, many thousands of unheard Americans, old and young, have found their voices, expressing themselves in a resonant affirmation of their life stories and cultural heritage.

[For further information on ESTA and on it's training programs, please contact ESTA at (212) 780-1928]

Susan Perlstein, M.S.W., founding Director of Elders Share the Arts, is an educator, social worker, organizer, administrator and an artist and author, writing on creativity, arts-in-education and aging. She is a consultant for The New York City Department of Cultural Affairs and the New York City Board of Education. In the Spring of 1997, Ms. Perlstein received the Tunick Award from the National Council on Aging for innovative and pioneering work in the field of aging.

Perioperative Audiotapes: Audio Rx for Surgical Patients

By Linda Rodgers, C.S.W.

Have you ever heard surgery described as a thoroughly delightful experience? So enjoyable that you'll look forward to repeating it as often as you can? Yeah, right! Neither have I.

All surgery is stressful and raises universal feelings of anxiety in patients of all ages. For many, it takes only one traumatic experience to produce lasting anxiety easily triggered by a subsequent need for surgery. On a global scale, we still don't know how to reduce harmful effects of anxiety and stress exacerbated by the surgical time frame. Nor do we really understand how best to protect patients from hearing damaging conversation and noise before, during and after surgery. We do know that psychological preparation for surgery enhances postoperative recovery, yet hospitals cannot afford the time or staff to work with patients preoperatively. Although it is well documented that hearing is the last sense to go (auditory pathways are not effected by anesthesia and hearing remains intact during surgery), surgeons and other medical professionals have largely ignored research findings. They have not yet seriously addressed the prevention of auditory perception under anesthesia, and with it, the traumatic recall for surgical events that follows when memory persists or remains buried in the unconscious.

Nothing will ever take the place of another human being offering warmth, support and comfort, but when direct contact is not available to surgical patients, perioperative audiotapes heard through earphones are a simple and cost-effective tool to help patients manage the surgical time frame more comfortably. Consider the following laundry list of commonly recognized problems confronting surgical patients.

Preoperative anxiety—so common that it's termed anticipatory anxiety—can start the moment we're told we need surgery, and is likely to include many of the following: fear of the unknown, of anesthesia and death, mutilation and pain. Patients are at their most vulnerable just prior to surgery, waiting in the holding area outside the operating room where there is a final feeling of loss of control in an unfamiliar environment which is staffed by strangers. For many there are additional feelings of isolation and helplessness...and mounting anxiety.

Auditory perception during surgery under general anesthesia is only one of the problems. Consider the plight of patients who are conscious during surgery under local or regional anesthesia. Example: orthopedic surgery requiring drills, reamers, oscillating saws and other noisy equipment used in the average operating room such as monitoring devices and alarms, ventilators, suckers, pumps, pagers, intercoms and telephones, together with the clanging of metal bowls and instruments. (The just audible rustle of leaves measures 10 decibels; a very quiet whisper, 20 decibels; a sucker in use, 75-80 decibels and a stainless steel bowl falling onto a tile floor, 108 decibels.) Is this restful or what? Olfactory sense remains intact for patients who are conscious, and they can smell their own flesh being cauterized. Normal operating room conversation and banter can be overheard as threatening or confusing, and while responses obviously vary from patient to patient, many report a growing sense of vulnerability ...and rising anxiety.

> *"We do know that psychological preparation for surgery enhances postoperative recovery..."*

For patients in recovery from surgery, the postanesthesia care unit can feel like a waking nightmare, particularly in large metropolitan hospitals where the pace is frantic and contact with staff limited to medical procedures. There is rarely time for reassuring emotional support, and patients experience everything from disorientation from surgery, anesthesia and other medications, to difficulty seeing and speaking, extreme sensitivity to light and sound, and discomfort related to the surgery itself and unpleasant postoperative procedures. While anxiety continues to mount...and mount.

Now consider the same pre-, intra-, post-operative scenes re-played. This time the patient equipped with tapes, walkman and earphones; each tape giving simple messages of information, reassurance and suggestions against a background of music designed to soothe and relax the listener. The pre-op tape acknowledges the presence of anxiety as patients - both at home and later in the hospital - wait for surgery to start. i.e. "The tape that you are listening to was made especially for patients to hear before they have surgery...this is a particularly difficult time for everyone, and so this tape was made to help you feel as comfortable as you can while you wait...." An intra-op tape prevents patients from being exposed to noise and conversation in the operating room, yet allows OR staff complete freedom to discuss anything they like without danger of being heard, and a post-op tape acknowledges discomforts inherent in early recovery, with specific suggestions to help patients manage this stressful period.

Based on my experiences as a cardiothoracic social worker at Mount Sinai Medical Center in Manhattan, on a review of the literature and on interviews with surgeons and anesthesiologists, I tailored my scripts to patients having general anesthesia or local/regional anesthesia. On the advice of a breast surgeon (who was also head of the Physicians' Orchestra), I wrote a one size fits all script for each surgical time frame, with the specific goal of preventing (or at least reducing) perioperative anxiety and stress. I also tried to avoid raising anxiety. While some patients want to know everything in detail, others panic at the word 'needle'. I tried to limit information and

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to keep it simple. No jargon. No theory. The timing of information is another important consideration, optimally given well in advance of hospitalization so that questions can be raised and answered leisurely rather than in the pressured time period preceding surgery when patients are least able to understand and assimilate threatening material.

Based on a musical background and training as a classical pianist and composer, I researched the choices of music for patients to hear perioperatively. In the process I learned about something called ANXIOLYTIC MUSIC (pronounced ank-see-o-lit-ic) which simply means music, or musical sounds, designed to reduce anxiety. Anxiolytic music treats sound softly and gently. There are no abrupt shifts in volume and nothing to startle the listener. Sound moves consistently, flowing smoothly, enveloping and sedating by avoiding traditional forms of music we have learned to anticipate. Anxiolytic music is best understood broken down into two categories. The first deals with familiar stuff, material so well known that we tend to overlook it. Familiar music evokes memories and associations different for each of us. The same Sinatra ballad that warms my nostalgic heart may remind you of a romance turned sour, and even the same Brahms symphony, exhilarating on Tuesday, may provoke aching sadness on Wednesday. It's hard to predict how any of us will respond to music that we know and since surgical patients are uncommonly vulnerable, it suggests a need for caution in selecting music for them to hear.

> *How to get them accepted and into use ... is another matter.*

Note: I should add that when patients express a musical preference, naturally it should be respected.

The second category deals with the structure of music - all the other stuff that we hear without tuning in completely - such as melody, harmony, rhythm, instrumentation and sound. Melodies are structured to create a beginning, a middle and an end. When we know the melody, we not only know where it's going, we know how it's going to get there. Try singing the following round out loud: " Row, row, row your boat gently down the stream, Merrily, merrily, merrily, merrily, Life is..." When you deliberately cut yourself off from singing "...but a dream", you're really rocking the melodic/lyrical boat! It's unsettling, not to be able to complete the phrase. Anticipating the melody's progression and then waiting for the melodic line to end creates expected tension: both mind and body held suspended until the melody ends. However, if we want surgical patients to relax, music without melody may be the most restful and comfortable way to listen. Harmony, similar to melody, is used principally to stimulate tension and sustain interest, so when we want surgical patients to relax, we'll give them simple, uncomplicated clear sounds to hear. Rhythm, with its primal connection to heart sounds in the uterus, is something we've all known and will never lose. The beat goes on in our own pulse. Anything above a normal heart rate of 72 energizes (marching band or aerobic fitness music) and below the rate of 72 tends to slow us down. Irregular beats are comparable to arrhythmia and usually used to produce a jarring effect. And so like music without melody and distinct harmony, an absence of rhythm with controlling beats allows us freedom to set our own individually rhythmic clock as we listen. Common sense suggests a choice of instruments resonating in mid-range. Recorders, piccolos and any high-pitched instrument will soon begin to feel like an assault on your head, while bassoons and timpani tend to vibrate uncomfortably in the low-end zone of the body. For surgical patients, some of the most soothing sounds include strings and woodwinds in mid-range (violins, cellos, oboes) in addition to piano and xylophone. Although mellifluous and lyrical, I avoided using the harp out of concern that it may conjure up the wrong message for surgical patients.

> *Anticipating the melody's progression and then waiting for the melodic line to end creates expected tension ...*

In summary, anxiolytic music avoids songs and familiar music that can trigger harmful memories and associations. It avoids melody, stimulating harmony, and rhythm that serve to arouse the listener. Instruments are chosen for their gentle and tranquilizing effects. Anxiolytic music is an especially user-friendly sound package for surgical patients. It is a uniquely calming and non-pharmaceutical form of audio analgesia designed to reduce anxiety and stress. Patients seem to like it.

But that doesn't mean perioperative audiotapes are being used routinely by patients, much less accepted by the established medical community. Hospitals and doctors are reluctant to approve new health interventions without first documenting statistically significant proof of their efficacy. Despite ongoing research and compelling data indicating broad benefits to patients using mind body interventions, hospital and managed care systems remain both indifferent to, as well as ignorant of, the literature. In their defense, and given the crisis in healthcare today, it's understandable that implementing perioperative audiotapes is not high on the priority list of the medical establishment. Although there are impressive numbers of healthcare professionals working within medical institutions to mount well-designed studies to document the psychological, medical and financial benefits of surgical audiotapes, progress is painfully slow. And in the meantime...patients are waiting....

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Musical Therapy in Hospice Care

by Rima Starr, M.A., C.M.T.

Today's health care worker must consider the total patient—a physical, psychological, spiritual and social being, reaching out to us for help. The medical profession is slowly becoming less resistant to the role of adjunct or alternative therapies, broadening their scope of treatment possibilities, awakening to the fact that therapy has moved beyond medicine.

Music therapy is an integral component of the interdisciplinary team of healthcare professionals at the Jacob Perlow Hospice, Beth Israel Medical Center in New York City. The focus is on comfort and on enhancing the quality of life of the dying patients and their families. Even when there is no longer the possibility of physical healing, meaningful changes often occur on emotional, spiritual and social levels - resolving lifelong conflicts, mending broken relationships and learning vital life lessons.

Lessening pain, facilitating life review, providing pleasant, often joyful, diversion, family bonding experiences, social stimulation, enhancing spiritual support and inspiration, reconnecting patients to their ethnic or religious background, relaxing or energizing, lessening anxiety and/or fear: these are the Hospice goals addressed by Music Therapy. The patient's self-esteem and sense of control is greatly enhanced by experiencing musical mastery activities facilitated by the therapist, thereby empowering the families in their caregiving role and enhancing their coping skills.

> *"... meaningful changes often occur on emotional, spiritual and social levels ..."*

"I can't remember when I've seen you this happy," said a patient's husband, as they shared their fond memories evoked by the familiar old songs they'd just sung. "It's been years since I've sung," said his wife with a proud smile. She seemed to welcome each song as one would a long-lost friend. Her affect brightened as she added maracas and other rhythm instruments to her musical expression. This eighty-four year old colon cancer patient and her husband of sixty years shared a joyous, empowering, nostalgic activity which was not illness related. She died three days after.

> *"Families ... are often elated to find a new caregiving tool."*

Music Therapy offers the demented or Alzheimer's Hospice patient a means of communication, of reconnecting to loved ones, a way out of isolation and withdrawal. The music center of the brain is the most primitive and the last to deteriorate. When verbal communication is no longer possible, music provides a new language, a means of self-expression: the patient who can no longer complete a full sentence, can often sing entire songs. Families who have cared for their loved ones for years, watching their painfully slow deterioration, are often elated to find their new caregiving "tool". The enjoyable musical activities learned in the therapy sessions can be incorporated into their daily routines. The language of music can thus restore their family bond.

Research has shown that music actually decreases pain perception by reducing muscular tension, lessening feelings of helplessness and by evoking emotions which trigger the release of endorphins, the body's natural opiates. Also, listening occupies some of the neurotransmitters, resulting in fewer available for sending pain messages.

"Music transforms me," said Jenny, a forty-two year old cancer patient, when asked what could be done to help her with the intense breakthrough pain she was experiencing at the beginning of her session. She was asked to choose a favorite song to be sung for her. She chose "Tell Me Why", a poignantly beautiful and timely old camp song. Jenny's grimaced expression softened as she surprisingly joined in the singing. Providing the harmony, she seemed to feel empowered by a sense of mastery and control, so important for cancer patients who have lost most things in their environment, including and especially their own body.

Her posture changed dramatically during that forty-five minute session, from being curled up in a fetal position to sitting upright in bed. Color returned to her cheeks as her face softened in a faint smile. Her energy level increased. "What a wonderful job you have," said Jenny, who was a successful, still-practicing Freudian psychoanalyst. "You leave so much happiness behind you." She reached for the tambourine.

A few days later, only two hours before her death, nine of Jenny's friends stood around her bed. "Sing to me, please;" those were her last words. Jenny had a peaceful death as her friends sang the last verse of her favorite song - "... because God made you, that's why we love you."

The eighty-six year old colon cancer patient awoke, as if from a brief nap, to the gentle sounds of Hungarian

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children's songs sung close to his ear as his wife looked on in astonishment. It remains a mystery how and why music pierced through the depth of his coma, singing him back from the silence.

Music speaks to us in ways that the heart and soul understand, working its wonders when all else fails. "Frequently the non-responsive respond; the belligerent cooperate; the guarded open up; the hopeless find renewed meaning." (Lane: Oncology Nurses Forum) This special healing occurs in both the patient and the caregiver. "The profound meaning of music and its essential aim is to promote a communication, a union of man with his fellow man and with the Supreme Being." (Stravinsky)

Rima Joy Starr, a Certified Music Therapist, is a classically trained singer with a background in opera and musical theatre. She holds a Masters Degree in Music Therapy from New York University and received advanced training at Israel's Rubin Academy of Music and at the Institute for Expressive Psychoanalysis in New York City. Ms. Starr currently hold the position of Music Therapist at the Jacob Perlow Hospice, Beth Israel Medical Center, where she works with dying patients and their families. She is also a nationally known public speaker, lecturing and presenting training workshops for caregivers, both professional and non-professional.

[For more information on Music Therapy or on starting such a program, please contact Rima Starr at (212) 420-2409]

Perioperative Audiotapes

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"Perhaps common sense will rule when doctors, hospitals, and HMOs are pressured by 'consumers'—the patients—who intuitively believe they need support and preparation for surgery, and who vigorously assert that need." (Dreher 1998) When patients call to order my surgical audiotapes, I routinely advise them to tell their surgeon or anesthesiologist, in advance of being admitted to the hospital, about their intention of listening to the tapes before, during and after surgery. If I hear a plaintive, "Suppose they say, No, what'll I tell them?" I swing into my best Patient-as-Consumer Advocate position and try to cover basic material such as: Notifying your doctors in advance gives them time to decide where to place the walkman during your surgery, and how to handle your earphones if they need to speak to you. Sterility is not a problem but you might want to put your walkman into a zip lock bag as protection for the walkman. Battery-operated walkmans cannot generate "electrical sparks" in the operating room because they are powered by batteries and not by electricity! (I checked this out with the engineering departments of several large Manhattan teaching hospitals.) The most you will need is some cooperation in changing tapes during the different stages of surgery, and someone in the OR will definitely be able to handle that for you. Using perioperative audiotapes is not exactly rocket science. How to get them accepted and into use by every surgical patient who wants them, is another matter.

> *"Sound moves consistently, flowing smoothly, enveloping and sedating by avoiding traditional forms of music ..."*

Some patients are more skilled than others in negotiating their rights as consumers. But for those who are easily intimidated by their doctor or ill prepared to navigate a complex medical/surgical system, health advocacy professionals are natural allies. Patients, acting as consumers, need to know how best to advocate for themselves, and healthcare advocates are uniquely qualified to help advance the concept of using perioperative audiotapes by informing and educating both the patients and members of the medical community.

Linda Rodgers, C.S.W., is president of the Audio Prescriptives Foundation, established as an education and research foundation producing perioperative audiotapes. A recognized composer and classically trained musician, she also sits on the boards of the Juilliard Council, the Hastings Center, the New York Hospital-Cornell Medical Center, the Alcoholism Council of Greater New York, the Brookdale Institute on Aging and the Citizens' Committee for Children of New York.

Sanctuary Gardens: Roots – Words – Meaning

by Topher Delaney

Sanctuary is a physical plan extolling the beauty of nature written in the lines of the earth. —Ralph Waldo Emerson

The word/concept SANCTUARY is derived from the Latin "sanctus," meaning holy. The word/concept GARDEN is derived from the Indo/European root of "gher," meaning enclosure. Through my work as an artist, as a gardener, and as a healer I seek to create secular sanctuary gardens in both literal and allegorical forms.

Nine years ago, the revelatory experience of breast cancer transformed my practice of the previous fifteen years designing and building gardens - gardens which wove distinct sculptures, paved surfaces, earth, water, and plants into three-dimensional informal and formal installations of gardens.

> *"This garden offers the community of this facility a sanctuary ... to restore a spiritual balance within the safety of the garden..."*

The first residential garden I was commissioned to do - three days out of the hospital - was "The Garden of Divorce," a garden which transformed. All the projects had been left unfinished by the departed husband, including the concrete terrace poorly installed by the same departed husband. In collaboration with Nina, all the previous dysfunctional physical elements were woven into the text of the land to create a unique expression of sculptural forms—the process of creation—the cultivation of the earth. The restoration of balance to an imbalanced environment has healed a significant trauma both for Nina and, ironically, for myself. Her garden is an aesthetic emotional sanctuary which we have transformed from a barren expression of unfulfilled promises into a dynamic garden of startling, complex forms. This is manifestly a personal sanctuary responsive to the unique requirements of an individual. Personally, this was the first designed garden completed after the light of mortality was lit. I was blind but now I see (just a little bit). The evidence of my mortality ignited a personal search for spiritual meaning in the creation of gardens - I literally focused on unearthing the symbols, the references, the physical manifestations of my/our (in collaboration with clients) spiritual relationship to the garden. This passion was motivated by my own personal search to recreate a balanced harmony - to comprehend the process of control - to transform an untended garden gone wild - to join in collaboration with personal clients and corporate clients to discover their respective boundaries - the creation of an internal order - the balance of form and function within nature which would contribute to the creation of a sanctuary.

At the same point in time I was creating the Divorce Garden, The Norris Cancer Center commissioned my firm to create a sanctuary garden on a one-acre site adjacent to the hospital (located in Los Angeles), which would foster an environment for patients, family members and staff in which these individuals could find solace surrounded by the beneficence of floriferous gardens. This garden was to be a spiritual resource for an outstanding medical facility.

We accomplished this request. *Boundaries.* A walled garden of bougainvillea brimming with color and thorns protects the visitor. *Water*. Water brims over sensual black forms of stone, constantly flowing, creating the sound of movement. *Color*. Dappled light, shifts through a cloud of lavender and pink petals. The canopies of jacarandas and Hong Kong orchid trees which are viewed not only from the ground plane, but also from the ten-story hospital wing. *Complexity, Cycle of Life.* The clouds of color disperse, transforming the grove of trees into a graceful, sculptural mass of branches. Across the series of descending terraces, thousands of iris bloom, extending the cycle of life another year. This is a dynamic garden of transformation. *Sensual Comfort*. Scented jasmine blooms on trellis frameworks which bisect the circular form of the garden, offering personal individual spaces for patients to sit on wooden benches amidst scented green walls. This garden offers the community of this facility a sanctuary in which to contemplate, to restore a spiritual balance within the safety of the garden - removed from the distractions and contusions which pull and push our psyches outside The Wall.

I have since created different physical forms in nature which respond to the request both personal and institutional to created sanctuary gardens:

- Bank of America of San Francisco–a one-acre roof garden, for the benefit of 2,000 tired employees. *Harper's Bazaar*, August 1994.
- Marin Cancer Institute, Marin, California - a 600 square foot sanctuary garden adjacent to the radiation waiting room. Materials: water, stone and plants which are used pharmacologically in the course of treatment of various cancers. *New York Times* Cover Home Section, December 29, 1994.
- San Diego Children's Hospital, San Diego, California - 6000 square-foot garden. See: *Gardens Illustrated*, August-September 1998.
- Alzheimer Garden, Corte Madera, California - Senior Access Center.
- Beth Israel Hospital North, New York, NY - 2000 square foot terrace garden commissioned for children residing at "The Inn".
- Highland Hospital, Oakland, California - a public hospital within which I have developed a learning museum throughout the hospital which focuses on the diversity and communality of cultural expressions. *Harper's Bazaar*, August 1994.
- Che Garden, San Francisco, California–a physical koan for meditation with an eight foot in diameter bowl of water lit by neon. See: *Metropolitan Home*, March-April 1997.
- 340 Lombard St., San Francisco–walled garden of giant timber bamboo. You enter through sandblasted

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Assistance Dogs in Medical Facilities

by Toni and Ed Eames

When nurse Mary Ellen entered Room 405 at St. Agnes Medical Center in Fresno, California, she was not only greeted by a smiling patient, but also by a Golden Retriever with a wagging tail! Toni was the patient and the wagging tail belonged to her guide dog Escort. Escort was present during Toni's pre-operative procedure and two-day hospitalization. In contrast, Nikki Deptula was not allowed to have her service dog with her during her hospitalization at Johns Hopkins.

Some medical facilities welcome disabled visitors accompanied by assistance dogs, while others attempt to exclude them. Some assistance dog partners are employed in medical facilities, while others are denied the right to bring their dogs to work. In many cases of access denial to medical facilities, claims have been filed against the hospital and these cases are working their way through the legal system. Hopefully, with greater understanding of the role assistance dogs play in the lives of their disabled partners, future illegal access denials will be avoided.

THE WORK OF ASSISTANCE DOGS

Guide dogs for the blind have been known in this country since 1929, but more recently, dog power has been harnessed to assist people with other disabilities. Guide dogs assist their blind and visually impaired teammates to safely negotiate their environment. They stop at curbs and steps, go around obstacles, locate entrances and exits and avoid moving objects including cars, bicycles, shopping carts and people. They are taught intelligent disobedience and will refuse a command perceived as dangerous or unreasonable.

Hearing dogs assist their deaf and hard-of-hearing teammates by alerting them to unheard sounds in the environment. These dogs make physical contact with their partners and lead them to the source of the sound. Dogs will alert to the smoke alarm, door knock or bell, telephone, alarm clock and kitchen timer. Among other things, dogs can be trained for a baby cry, emergency siren or the partner's name.

Service dogs assist people with physical disabilities in a variety of ways. One of their universal tasks is retrieving requested or dropped items. They also turn switches on and off, open and close doors, push elevator buttons, pull wheelchairs and act as support for people with balance problems.

ASSISTANCE DOGS IN MEDICAL FACILITIES

Toni was driven to her out-patient post-surgery chemotherapy treatments by a friend. What role did Escort play in this setting? He expertly guided her into the facility, found an empty seat and followed the nurse into the treatment areas. During her hospitalization he was available to assist her to safely ambulate prior to her release. As a trained guide, he helped her skirt other patients, portapotties, meal trays and wheelchairs as the team navigated the hospital corridors. In similar fashion, blind visitors and employees need to be mobile and their guide dogs are the means of achieving this goal.

> *"It is essential to know what the dog does for the disabled partner."*

A hearing dog would alert his/her hard-of-hearing or deaf partner when called for examination or treatment in an out-patient setting. The dog would be helpful to his hospitalized partner in many ways. If the bedside telephone rings, equipment warning alarms sound or a staff member wants to get the patient's attention, the hearing dog would go into action. Deaf or hard-of-hearing visitors and employees also depend on the alerting services of their hearing dogs.

In an out-patient facility, service dogs would assist their partners by pulling the wheelchair, provide balance and support for those with unsteady gaits, pull open heavy doors and push elevator buttons. Had Nikki Deptula been allowed to have her dog in the hospital, he would have retrieved her cane and assisted her to ambulate as part of her recovery process. Service dogs provide these and many other needed tasks for physically disabled visitors and staff members.

REASONS FOR ASSISTANCE DOG EXCLUSION

Based on the experience of people with disabilities denied the right to be accompanied by their canine assistants in medical facilities, especially hospitals, a variety of reasons have been cited. Among these are spread of disease and infection control, fearful or allergic patients or co-workers, misbehavior of the dog, unwillingness of staff to care for the dog and misunderstanding of the dog's function.

According to epidemiologists, the probability of transmission of diseases from canines to humans is insignificant. For contagion to occur, vulnerable humans would have to come in direct contact with canine feces or urine. The probability of this happening is extremely remote. According to these same experts, the risk of sick assistance dogs in hospitals is certainly much less than the risk of the presence of sick visitors and other patients.

Balancing the rights of patients and co-workers allergic to or afraid of dogs with the rights of those partnered with assistance dogs is a difficult task. In most circumstances, dog phobic or allergic people could easily avoid interacting with a disabled visitor, patient or staff member accompanied by an assistance dog. Although a small minority of patients express dislike or fear of dogs, the vast majority express pleasure and openly welcome canine visitors.

Concern that dogs may be disruptive and poorly behaved seems to be based on lack of knowledge about working canines. Assistance dogs are carefully selected and go through an intensive training period. They are under the control of their disabled handlers and behave properly in public places. Dogs should lie out of the way and not interfere with medical procedures.

Whether a disabled patient is being treated in the hospital or as an out-patient, medical personnel are not required to exercise, feed or care for the assistance dog. If the disabled partner is not able to care for the dog then he/she must make arrangements for someone else to do so. In many cases, however, nurses and aides vie for the opportunity

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Assistance Dogs

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to take care of the dog.

At first glance, the position that staff can provide all the services needed by a hospitalized patient seems reasonable. Based on such a belief, the assistance dog's presence is not needed. This assumption disregards many of the work activities performed by assistance dogs in hospital settings such as those previously described. Frequently, nurses and aides are overworked and cannot respond immediately to the needs of their patients, while the canine partner is always ready to assist. An additional element overlooked by those fostering this view is the disabled person's perception of the dog as intimately intertwined with his/her life. They are a team. The decision to work with an assistance dog is not taken lightly. Working with the trained dog fosters a sense of independence and self-confidence often not known before. The bond is so strong, separation frequently causes increased stress for both dog and patient.

Going beyond the in-patient setting, there are some situations in which hospital authorities claim visitors and employees do not need their assistance dogs because other staff members can do whatever is needed. When we were denied the right to visit a friend in St. John Medical Center in Tulsa, Oklahoma (see *Nursing Management*, 1997), the administration claimed it was offering reasonable accommodation by providing the guiding services of an untrained staff member. In some employment cases, the administration claims other staff members can provide all the service needed by a disabled employee and, based on this mistaken belief, has barred the presence of the assistance dog.

WHAT'S THE LAW?

The Americans with Disabilities Act of 1990 (ADA) is frequently cited as the law guaranteeing access to all places of public accommodation, including hospitals, for disabled people accompanied by assistance dogs. However, well before the ADA became law, Section 504 of the Rehabilitation Act of 1973 and its subsequent re-authorization prohibited discrimination against people with disabilities in federal programs and all institutions receiving federal funds. Over time the issue of the rights of blind people to be accompanied by guide dogs in medical facilities was addressed by the Department of Health and Human Services (HHS) under Section 504. In a memorandum dated March 24, 1988, HHS determined that guide dogs must be permitted in all areas of the hospital with the exception of those in which the dog would threaten the ability of the medical facility to provide its services to patients. This document makes clear that a denial of access must be based on a real rather than an assumed threat to the medical service provider receiving federal funds. Stereotypes or past experience with other guide dogs cannot be the basis of denial. Since all hospitals receive federal funds, this memorandum applied to visitors, patients and employees. After the passage of the ADA, this mandate was extended to hearing and service dogs.

> *"Frequently, nurses cannot respond immediately, while the canine partner is always ready to assist..."*

THE ROLE OF THE PATIENT REPRESENTATIVE

To adequately represent a disabled patient partnered with an assistance dog it is essential to know something about what the dog does for the disabled partner. It would also be helpful for every medical facility to develop specific policies concerning assistance dogs. Such policies must conform to current legal mandates. Once policies are established, the role of the patient representative would be to make sure these policies are fully implemented.

References

Eames, Ed and Toni, "Interpreting Legal Mandates: Assistance Dogs in Medical Facilities," *Nursing Management*, June 1997, 49-51.

Additional Sources

For additional information about assistance dogs and their disabled partners, see Eames, Ed and Toni, *Partners in Independence: A Success Story of Dogs and the Disabled*, Howell Book House, New York 1997, and *A Guide to Guide Dog Schools.*

For further information about consumer organizations, current access cases, existing training programs, etc., contact the International Association of Assistance Dog Partners, a consumer advocacy organization. IAADP publishes a quarterly newsletter, Partners' Forum and has an Information and Advocacy Center which can be contacted by phoning 810-826-3938. IAADP's web site is www.iaadp.org.

Toni Eames, M.S., and Ed Eames, Ph.D., Adjunct Professors of Sociology at California State University, Fresno, travel and live with Golden Retriever guide dogs Escort and Echo. They publish in many animal- and disability-related magazines. They are itinerant educators and do workshops for veterinary schools and professional associations, graduate social science programs and organizations dealing with the human/companion animal bond. Ed and Toni are board members and officers of the International Association of Assistance Dog Partners. Toni was inducted into the National Hall of Fame for Persons with Disabilities in 1998.

Sanctuary Gardens: Roots - Words - Meaning

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glass walls, symbolic of darkness and light, into the core of the garden. See *Metropolitan Home*, March-April 1998.

Our residential work is extensive. These two particular gardens offer insight into two significantly different approaches to sanctuary. The Che Garden exemplifies contemplation focussed on a central kinetic object; 340 Lombard exemplifies contemplation on the void, the removal of form to the position where the boundaries are the dynamic elements of the core.

"What are bulbs?" he put in quickly.

"They are daffodils and lilies and snowdrops. They are working in the earth now - pushing up pale green points because the spring is coming."

"Is the spring coming?" he said. "What is it like? You don't see it in rooms if you are ill."

The Secret Garden
Francis Hodges Burnett

Topher Delaney received her B.A. in Landscape Architecture at the University of California at Berkeley. During her twenty-five year career as a landscape designer, contractor and artist, she and her design firm Delaney Cochran & Castillo have been involved in a wide variety of garden projects. Ms. Delaney's work is currently featured in the book Paradise Transformed - Gardens of the 21st Century.

Animal Assisted Therapy

by Cynthia Kemp

The positive influence of animals in the healing process has been long observed and is now being utilized in a variety of healthcare settings. In fact there are an estimated 2000 animal assisted therapy programs operating in the United States today.

Borrowing from historical perspective, Florence Nightingale, in her journal writings from the Crimean War in 1854-1856, reported the power of animals to allay anxiety and provide comfort. Today, scientific studies have quantified the association between pets and reduced stress, lower blood pressure and increased survival rates in patients hospitalized with coronary heart disease. It has been suggested that pets provide a spiritual component to healing and bring out compassionate behavior in people.

St. Vincent's Hospital in Greenwich Village, New York, has undertaken a study to demonstrate an improvement in both patient recovery and staff satisfaction when dog visits are a part of the treatment program. Ellen Martin, a former Sarah Lawrence professor in the Health Advocacy Program and Director of the Patient and Family Relations Department at St. Vincent's, has spearheaded the study. Gaining internal alliance from a multi-disciplinary hospital committee including Nursing, Infection Control, and Legal Affairs, among others, and receiving approval from the New York State Health Department, took two years to accomplish. The results of her efforts are impressive.

On a quantitative level, patients report improvement in attitude and outlook as measured by a pre/post questionnaire. Importantly, staff satisfaction and morale has been rated very high (5 on a 5 point scale) when evaluated in the context of dog visits.

> *"To watch a chronically ill patient with self-reported feelings of depression and hopelessness, light up and laugh when one of the pet-therapy dogs visits, is a profound experience."*

Qualitatively, having personally observed the behavior and reaction of patients to dog-visits, the positive impact is undeniable. To watch a chronically ill patient with self-reported feelings of depression and hopelessness, light up and laugh when one of the pet-therapy dogs visits, is a profound experience.

Ms. Martin is presently compiling the data and plans to publish the findings in key journals shortly.

Reflecting the growing data, there are a number of academic institutions adding pet-therapy specific programs. These include veterinary schools as well as liberal arts colleges. Mercy College in Dobbs Ferry, New York, has a certificate program in Pet Assisted Therapy. Their goal is to provide the theoretical background and practical experience needed by professionals interested in implementing the therapeutic benefits of the human/companion animal bond.

The peer-reviewed journal, *Alternative Therapies*, concludes in its July, 1997, article that "the health value of pets is so compelling that if pet therapy were a pill, we would not be able to manufacture it fast enough." From a cost-control perspective, it is also suggested that therapies that keep patients out of physicians' offices are likely to be favored and reimbursed by health maintenance organizations.

There are a number of valuable resources available for those interested in further pursuing the subject of animal assisted therapy:

1. The Delta Society: 1-800-869-6898
2. Mercy College: Certificate Program in Pet Assisted Therapy Facilitation
3. www.aat.org/
4. Alternative Therapies, July 1997, Vol. 3, No 4. "The Healing Power of Pets" by Larry Dossey, MD

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Holistic Nursing: Nurturing and Balance

by Irene Selver, M.A.

"If you treat everything with love, honor and respect, the Universe will provide." So states Leighsa Sharoff, a certified holistic nurse who teaches the holistic approach at the School of Nursing at Long Island University's Brooklyn campus. With a Masters in Psychiatric Mental Health, she came to her approach in nursing through her practice as a pain management specialist.

Medicine today is moving away from the paternalism that frequently characterizes the patient/doctor relationship, with consumers asking to actively participate in their own well-being. According to Ms. Sharoff, not only do patients want to make informed decisions about their care, but educated and informed consumers are also looking for ways to gain control over their pain, both physical and spiritual/psychic pain. In the holistic model, the patients must be able to participate in their own healing. "Pain often keeps one bound to what one is while experiencing the pain," says Ms. Sharoff. Holistic nursing practices offer several modalities through which to "promote health, facilitate healing, and alleviate suffering" (Code of Ethics for Holistic Nurses). By helping patients to honor the pain, to recognize the pain, to think of the pain as only a part of the whole, the holistic approach helps them regain the ability to be what they were without the pain, or to be who they are while incorporating the pain.

Ms. Sharoff speaks of the essence of holistic nursing as "being present in the moment with the patient." With an understanding of the body-mind-spirit as one, the holistic practitioner becomes an active listener, making direct contact, through touch, through eye contact, through words, or an attentive silence. Defining holistic as "emphasizing the organic or functional relationship between parts and wholes" (Webster's Seventh New Collegiate Dictionary), the practitioner, having established a caring one-on-one contact, becomes a therapeutic partner in helping patients stay in, or regain, control over their bodies and spirit. Thus the holistic nurse is available to participate in the full spectrum of the healing individual.

Holistic nursing for Ms. Sharoff is "a way of being," utilizing different healing modalities. Biofeedback, the monitoring of internal body states with the use of sensitive electronic instruments, is one such modality. Aromatherapy, using the pure essence of oils to awaken a memory, soothe anxiety, relieve stress, is another. Music therapy, such as the use of tapes designed to encourage relaxation, or the use of anxiolytic music as detailed in the accompanying article by Linda Rodgers, is a third modality used in holistic nursing. Therapeutic touch, where the practitioners use their own energy field to help release trapped energy (the hot spot of pain) in the patient, facilitates the flow of healthy energy once again through the body.

Deep-breathing relaxation and interactive guided imagery are two modalities in which Ms. Sharoff is a specialist in her own practice of holistic nursing. Describing how often, as adults, we breathe engaging our neck and shoulders, she teaches relaxation through abdominal breathing, allowing, through lung expansion, the natural oxygenation of the body. Imagery is a means by which, through the creative essence of the mind, a person establishes for himself or herself a "safe place" to go to in times of stress, of anxiety.

> *"Patients must be able to participate in their own healing ..."*

As a teacher of holistic nursing, Ms. Sharoff speaks of the need for practitioners to increase their own personal sense of self-awareness: "Holistic nurses strive to achieve harmony in their own lives and assist others to do the same" (Code of Ethics for Holistic Nurses). Through the use of the modalities mentioned, Ms. Sharoff facilitates her students' own recognition of who they are, and helps them "honor their own weaknesses and strengths". Starting from the premise that true healing starts from within, she assists them in healing themselves first to enable them to then participate in the healing process of others. "Being holistic," says Ms. Sharoff, "is a way of being interactive with, and caring for, the self, Mother Earth and the Universe."

Leighsa Sharoff sees the origins of holistic nursing in Florence Nightingale, "the mother of nursing," who understood and addressed a need essential to healing: the creation of a clean and soothing environment in which the healing process is nurtured, an atmosphere subsumed in today's highly technical, sterile health care centers. Beginning in the early 1971, however, holistic practices began to re-emerge. The American Holistic Medical Association (AHMA) was founded in 1978. The American Holistic Nurses Association (AHNA) was founded in 1980 around the philosophical belief that "health involves the harmonious balance of body, mind, and spirit in an ever-changing environment" (AHNA position statement). In 1992, the National Institute of Health (NIH) set up the Office of Alternative Medicine, today call the National Center for Complementary and Alternative Medicine, created in recognition of complementary medical practices and of the need to integrate all modalities into patient care. And in November of 1989, the American Holistic Health Association (AHHA) was founded as an educational, informational and resource service for those seeking a holistic approach to wellness. (See accompanying article by its president, Suzan Walter.)

Ms. Sharoff adds that within the last five years holistic nursing has become a recognized and accepted approach to patient care. She states that it is no longer a taboo and has become easily accessible in hospital settings. She advises asking for the psychiatric nurse liaison to help identify holistic nursing practitioners, but adds that all bedside nurses are aware of such practitioners and can also help facilitate access to appropriate staff.

Irene Selver, HA '89, has been involved in various areas of HIV/AIDS education, and is currently working in the Client Advocacy Department of the Gay Men's Health Crisis in New York City. She is co-editor of this publication.

One Pathway to Pain Management

by Christine L. Dyer

A Short History of Medicine: "Doctor, I have a back ache."
2000 BC "Here, eat this root."
1000 BC "That root is heathen, say this prayer."
1850 AD "That prayer is superstition, drink this potion."
1940 AD "That potion is snake oil, swallow this aspirin."
1985 AD "That aspirin is ineffective, take this muscle relaxant."
2000 AD "That muscle relaxant is artificial. Here, eat this root!"

I was recently diagnosed with a rare genetic disorder called Ehlers Danlos Syndrome (EDS), as well as with fibromyalgia and osteoarthritis of the spine. For the previous 12 long years my condition had been misdiagnosed while I experienced chronic back, hip and leg pain along with periods of muscle weakness leading to immobility. I tried conventional (or allopathic) pain control and strengthening treatments including pain medications, muscle relaxants and physical therapy. I was put in traction and received epidural steroid injections. I was either being physically manipulated, which led to further pain, or given medications that helped with the pain but created a drug haze that interfered with my life. The medical community was stumped, and I, needless to say, had a sense of hopelessness. The more pain and weakness I felt, the more depressed I became. But before I sank inexorably into depression, I determined to explore my alternatives. I want to share my experience with four non-conventional approaches that I have used successfully for pain control: Psychology of Mind/Health Realization, deep-water exercise, craniosacral therapy and acupuncture.

First, believing that a healthy mind leads to a healthy body, I explored a new model of psychological understanding called Psychology of Mind (POM)/Health Realization. The basic premise of the three principles of POM—Mind, Thought and Consciousness—is that in every moment, the mind creates thoughts and those thoughts appear real via our senses through our consciousness. Each person's reality is linked to her thoughts in that moment, and it is the ability to think that determines the quality of life experience. In other words, the process of thinking rather than the content of thought is what is important. POM practitioners believe that everyone has the ability to realize good mental health. At first, I thought that this was feigned optimism; but as I began to understand how the thought process works, I became hopeful as well. Weakness or pain meant that I was trapped in my own dysfunctional thinking. Eventually, I began to realize that my moods impacted my thoughts and feelings, and thus affected my ability to look at my illness objectively. When I was in a good mood, my thoughts were positive, my decisions sound, and my level of pain and disability were manageable; when I was in a low mood, my thoughts were negative, I was not able to see my limitations as clearly and the pain and disability were exacerbated. I learned how to be a good listener, not only to others, but also to myself, and I began to see myself as an intelligent person with certain physical limitations. The principles of POM helped me to become hopeful about living a successful and fulfilling life despite my illness. Once I had a better understanding of how my mind effected my physical health, I was able to pursue alternative methods of pain control and physical fitness.

One method was deep-water exercise recommended to me by a doctor I met at a POM workshop who had similar experiences with pain and muscle weakness. He talked about a Russian doctor, Igor Burdenko, who founded the Burdenko Water and Sports Therapy Institute in Lexington, Massachusetts. He explained that the weightlessness experienced in deep water is ideal for those of us who need to strengthen and tone our muscles without subjecting our bodies to the impact and pressure that comes from traditional land exercise. Water exercise also strengthens the heart muscle, which leads to better circulation. The Institute claims among its clients numerous sports celebrities who come to recover from injuries, as well as others, like myself, who suffer from chronic pain and physical disabilities. At the Institute I was presented with a flotation belt and two strange looking barbells with Styrofoam instead of weights on the ends. Over the next 10 visits I learned deep-water exercises that helped me achieve muscle tone and strength, exercises I could do without experiencing pain. The more muscular strength I built, the less frequent the periods of weakness, disability and pain.

The physical gains of water therapy were wonderful; the emotional gains were a complete surprise. When I got into the water I immediately felt the stresses and strains of the day melt away. Working out in water is ideal because it serves as a constant cooling mechanism for the body, which allows for longer workouts. During my days of land exercises I was hot and tired and in pain most of the time. I simply had no stamina. In the water I can water-walk for 20 minutes for a great aerobic workout, then do muscle toning and strengthening exercises for up to 40 minutes at a time.

At Burdenko, I was introduced to craniosacral therapy, a technique used to correct the balance of cerebrospinal fluid, which surrounds and moves the brain, spinal cord, sacrum and connecting membranes. I found this method particularly helpful when my lower back and hips were stiff and in pain, and with neck pain and headaches. During periods of chronic pain that didn't lessen with craniosacral therapy or water therapy, I scheduled acupuncture treatments.

> *"Each person's reality is linked to her thoughts in that moment ..."*

For many, acupuncture is an excellent method of muscular and nerve pain control. Traditional acupuncturists believe that there is a basic energy of the

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One Pathway to Pain Management

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body called qi (pronounced 'chee'). The aim of traditional Chinese acupuncture is to regulate the flow of qi along pathways or meridians that run throughout the body. When your qi is balanced and flows without obstruction, your health is restored. Western doctors do not usually believe in the power of qi, but many accept the efficacy of acupuncture. Their theory is that acupuncture releases beta-endorphins and other body chemicals that reduce pain. No matter. For me, acupuncture reduces or eliminates pain without negative or dangerous side effects.

Conventional pain control techniques did not work well for me, but I have been able to work out a system of alternative therapies that have not only helped me manage pain, but have changed the way I look at my own disability. For many people—especially those suffering from cancer or AIDS—pain control is best achieved through complementary medicine, a combination of conventional and alternative medicine. For those of us who experience chronic pain, an understanding that medical techniques can "complement" each other is imperative.

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Massage: Mystique, Managed Care, and Money

by Melissa J. Haller

What began as a simple inquiry into massage therapy as a component of Complementary (Alternative) Medicine turned out to be something far more complicated and fascinating than I could have imagined. My interest in massage therapy is threefold: (1) one of my best friends is a massage, therapist (lucky me); (2) other alternative therapies such as homeopathy, chiropractic care, and acupuncture were far more readily "accepted" than massage, yet massage is one of the three most requested alternative therapies; and (3) I was fortunate enough during one hospital stay to receive reflexology and during another a full massage, which improved my spirits immensely. There is nothing like someone rubbing creme on your foot after IV's have been changed!

My investigation into how this "alternative" might be covered by mainstream insurance began with my friend, a licensed masseuse with a following from women with pre-natal difficulties to avid skiers. I asked her if she had any clients who were covered by health insurance for her services. No, she said. Besides, for her clientele, a $100 per hour fee was not an issue. Massage could, however, be covered if it was considered "physical therapy." My next move was to call Kaiser Permanente, my old insurance company. Paul, the customer service representative, was taken aback by my question about coverage (the length of his pause after I posed my question was noteworthy). "It depends on your type of coverage, POS or HMO?" was his first reaction. In fact, however, massage therapy was not covered under either plan but "physical therapy" was covered under both, provided that a primary care physician (an MD - the mainstream folk) clears the massage therapy. According to Paul, "In reality, it is all in the terminology." My curiosity was now at an all time high! Both an insurance representative and an alternative therapy provider had implied that this is a semantic game.

My next stop was the Westchester phone book under "massage therapy." The ad for Westchester Massage Therapy read, "Most Insurance Accepted" (and specified that this was a "Non-Sexual Service.") "It depends on the type of insurance" was the response to my query at Westchester Massage Therapy. Mainly No Fault or Workman's Compensation cover the service. At yet another place I was told there was no coverage for massage but I could be referred to a "cash lady." At best about 25 percent of a massage service may be covered by health insurance. Not much coverage in my estimation.

My last stop in trying to decode the validity of massage was New York Magazine. In the back section they list massage, to wit: "Oriental Exotics" and "Natalie from Moscow." It seems the two biggest problems with mainstreaming this type of service are (1) fraud (name-gaming a medical need) and (2) sexual stigma attached to massage or "touch". At a health fair recently my stressed-out boyfriend who has back problems took advantage of a five-minute chair massage. Not only did his attitude improve after the massage, but his shoulders did not slump as much. Perhaps health insurers should reconsider. As preventive health, massage could be truly cost-effective

> *"Both an insurance representative and an alternative therapy provider had implied that this is a semantic game."*

Melissa J. Haller is currently a student in the Health Advocacy Program with a special interest in mental health issues. With a B.A. in Business Administration from the University of Cincinnati, she has worked in marketing and management for a community trading agency.

Patients' Rights Legislation: Elusive or Illusion?

By Karen Crimmins, M.A.

In a continuing effort to fulfill his elusive election promise to improve the American healthcare system, President Clinton created a Health Care Advisory Commission in 1997 that would identify problems and submit possible solutions. This Commission introduced a healthcare Consumer Bill of Rights in November of that year. From early 1998, pressure on Congress to pass regulatory legislation relating to HMOs continued from the White House and from consumers, spurred on by the medical profession. Finally, as the November elections loomed closer, the urgency to present stricter federal legislation on managed care organizations appeared to encourage productive efforts.

> *"... public pressure will force the enactment of 'significant pieces' of patients' rights legislation..."*

In late July, the House of Representatives defeated by 5 votes the Democratic sponsored Gephardt-Dingell-Ganske Patients' Bill of Rights Act (H.R. 3605). Instead, the House passed, by a narrow margin of 216 to 210 the Patient Protection Act (H.R. 4250) sponsored by House Speaker Newt Gingrich (R-GA), which President Clinton threatened to veto.

Senate Democrats proposed legislation identical to the House Democratic bill, while Senate Majority Leader Trent Lott presented another GOP plan (S. 2330). Nevertheless, on October 9, the Senate voted to reject a Democratic move to take up a bill to define patients' rights and regulate managed care organizations.

The accompanying chart with information provided by Families USA compares the proposals of the GOP and Democratic bills as they relate to basic healthcare consumer protections.

Republicans complain that the Democratic legislation, by including so many additional mandates, would create too strong a Federal Government authority over the insurance industry, and would greatly increase costs and reduce access. They suggest that state laws provide adequate protection for the majority of those insured by HMOs. The Democrats and their defenders argue that state laws are not uniform concerning protections. They assert that HMOs must be held liable for medical decisions. They also believe that Republican mandates to expand medical savings accounts would segment the insurance market and make it harder for older and sicker consumers to obtain affordable quality medical care.

While the insurance industry, in concert with business-sponsored organizations, has spent millions of dollars lobbying against restrictive legislation, it supports many of the Republican mandates. The Democratic legislation has backing from the White House as well as from the AMA, the A.F.L.-C.I.O., and health advocacy groups such as Families USA.

Now that Congress has adjourned, what is the future of patients' rights legislation? Both foe and friend agree that the issue of basic consumer rights and regulation of HMOs will resurface. In a personal interview, Ron Pollack, Executive Director of Families USA and a member of the President's Health Care Advisory Commission, stated his belief that public pressure will force the enactment of "significant pieces" of patients' rights legislation during the next Congress. He considers the "toughest issue" for compromise to be HMO liability. Yet, he also believes that meaningful remedies must be found in order to make HMOs responsible for their decisions. Both Families USA and AARP have publicly insisted on a strong and independent external review process as their major advocacy concern. Mr. Pollack described the external review as the first link of the "whole process" of consumer protection, followed by HMO liability and consumer assistance provided by an advocate or ombudsman.

In answer to the critics of HMO legislation and doomsday predictions, Mr. Pollack pointedly stated that he does not think that such mandates are the beginning of the end for HMOs. These directives would merely establish a greater accountability to the consumer. Once ground rules are in place, it would be expected that managed care will be able

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Basic Consumer Protections: How the Federal Bills Compare

Managed Care Consumer Protection	Gingrich	Kennedy/Daschle	Lott
	Plan	Gephardt/Dingell	Plan
Emergency Room Access	W	S	X
Access to Out-of-Network Providers		S	
Specialist Can Be Primary Care Provider		S	
Standing Referrals to Specialists		S	
Direct Access to OB and GYN for Women	W	S	X
Continuity of Care When Physician Leaves Plan		S	X
Access to All Prescription Drugs		S	
Independent External Review of Complaints	W	S	W
Independent Consumer Assistance Program		S	
Disclosure of Treatment Options Required	W	S	X
Prohibit Financial Incentives to Deny Care		S	
Access to Clinical Trials		S	
Right to Sue for Damages		S	

S Provides strong protections for all consumers with individual or employer-based insurance coverage
W Provides weak protections to all consumes with employer-based health coverage
X Provides weak protections in 1 in 3 consumers with employer-based health coverage

Information provided by Families USA

A New Medical Specialty: Good For Patients?

by Patricia Lafferty, R.N.

On my way to interview Dr. Robert Wachter in his office at the University of California San Francisco, I pondered the formation, some twenty-five years ago, of the National Society of Patient Representatives, a new group of health professionals dedicated to patient rights and patient advocacy. Now a new and growing medical specialty, prompted by a concern for patient well-being, has recently formed its own professional organization: the National Association of Inpatient Physicians.

Called a "hospitalist" or "inpatient physician" this specialist takes over the care of patients at the time of their admission to the hospital until discharge home. Dr. Wachter, Associate Chairman of Medicine, describes the implementation of the inpatient physician program at UCSF as a "powerful idea." He is visibly enthusiastic about seeing this idea in action and growing successfully. He emphasizes the importance of communication, and believes it has been the key to the success of the University of California's innovative program.

Dr. Wachter's staff of eight physicians, assisted by residents, cares for ten to twelve patients at a given time, providing their direct patient care. Continuity is ensured by a maximum number of assigned days in a row. Effective communication is described as a steady flow of information by computer or fax to the primary-care physician who has referred the patient. An admission note and phone call initiate contact, followed by automatic copies of all progress notes and final discharge summary when the patient is referred back to his primary physician. Phone calls are ad lib and the primary physician often visits during the hospitalization.

> *"... a higher premium will be placed on hospital skills, experience and availability."*

Few physicians are reticent to turn over their patients. While some doctors prefer to preserve continuity and want to maintain acute care skills, and primary physicians in community hospitals may wish to continue the traditional role, the number of hospitalists is increasing steadily and there are now more than 2000 across the United States.

Dr. Wachter focused on the concept four years ago. His article "The Emerging Role of Hospitalists in the American Health Care System" was published August 15, 1996, in *The New England Journal of Medicine*. In this article, co-authored with Dr. Lee Goldman, Chairman of Medicine at UCSF, Stanford, he describes the realities of managed care and its emphasis on efficiency. He anticipated a rapid growth of hospitalists who would manage the care of hospitalized patients the same way the primary physician manages the care of outpatients.

Citing the central role of these physicians in Great Britain and Canada, Dr. Wachter feels that the role for this group will grow now both in and out of academia, especially in areas where managed care predominates, such as in San Francisco. Because of cost pressures, managed care organizations will reward professionals who can provide efficient care. In the outpatient setting, the primary physician, no longer responsible for responding physically to condition changes or emergencies, is able to provide care for a larger group promptly and efficiently. Dr. Wachter notes that although many physicians have exceptional hospital skills, he questions whether high-value care can be delivered by physicians who spend only a small fraction of their time in this setting. As hospital stays become shorter and patients sicker, he believes a higher premium will be placed on hospital skills, experience and availability.

As for hospitalists in academia, Dr. Wachter believes that twelve months of increasingly intense care of inpatients is a formula for burnout and a three- to six-month commitment more sustainable. He suggests consulting in or out of this specialty in the off months, and in academia creating a core group of faculty members whose inpatient work is more than a marginal activity and who are thus committed to quality improvement in the hospital. Highly skilled and experienced, they will offer better supervision of house staff and improved patient teaching,

Objections to the hospitalist program,

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to achieve its goal of effective healthcare. In addition, the Congressional Budget Office and independent surveys have demonstrated that the increase in employers' premiums to cover these additional consumer protections would be minimal.

In the quest for this so-far elusive patients' rights legislation, we health advocates also have responsibilities. In this time before the next Congressional face-off we should continue to keep well informed and be willing to actively educate others. In addition to contacting our Congressmen and women, Mr. Pollack suggested sending letters to the editors of regional and national newspapers and publications, and participating in public forums such as radio programs or local-level meetings. At the most basic level, we can also assist in the cause by informing our family and friends about the issues and soliciting their help. In other words, we all must contribute to the momentum that has already been initiated in order to prove that the need and the desire for patients' rights and healthcare consumer protections on the national level are not merely an illusion.

Karen Crimmins, M.A., has a special interest in public policy. She is currently the advocate for the disabled for her church parish, enabling people with disabilities and their families to participate in the Parish community.

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however, come from primary physicians and other specialists. Some primary physicians prefer to manage their own patients, and some specialists believe that fewer consultations and loss of income will result. These objections can impede implementation of new programs. Dr. Wachter believes that flexibility in programs can allay fears, although he feels that there are strong forces compelling growth in his new specialty. Fragmentation is a concern to many, but although having one's care assumed temporarily by another doctor is a transition for the patient, acceptance has been quite high.

In 1978 physicians spent half of their time in hospitals caring for 10-12 patients at a time. Now only 10% of their time is spent there. Hospitalists hired by the University of California, many of whom are former chief residents, are 20% busier than two years ago and more than 20% of medical residents are interested in this specialty. According to 1996 statistics, hospitalizations are 15-25% shorter and costs 15-25% lower.

Being on-site in the hospital daily has advantages to both staff and patients. Hospitalists may not be familiar at first but this is balanced by constant availability. Working relationships with other departments can be collaborative, system failures identified and corrected and more support time is available to family members.

At a time of continuing criticism of managed care and serious attempts to legislate the rights of patients, the goals Dr. Wachter describes are timely: improved clinical outcomes, lower costs, better education for physicians and greater satisfaction for patients.

The concept of the hospitalist *is* a powerful idea. After interviewing Dr. Wachter and reviewing his published material, I also believe he is a powerful patient advocate.

Patricia Lafferty, R.N., is a former president of the New York Chapter of Patient Representatives and board member of the National Society of Patient Representatives. She is now retired and living in California.

[We'd like to know what you think about the "hospitalist" idea. E-mail your opinions/ experience to Healthad@mail.slc.edu]

Director's Desk

by Marsha Hurst, Ph.D.

"How can you think and hit at the same time? " — Yogi Berra

As befitting a health care professional, I started as Director of the Health Advocacy Program on July 1. Like a new medical resident I found myself immediately immersed in the work of the Program, trying to "think and hit" at the same time. Unlike the new resident I am also a well-seasoned member of the Program faculty. Most days I feel right at home, touching base with alumnae I have taught, planning a meeting with faculty colleagues, and, of course, preparing my own courses. Yet, I am amazed at how much there is to learn, how many different aspects there are to running the Program (Mary's the organizational maven here) and how many new adventures in advocacy there are to pursue.

These days it is almost trite to talk about the rapidity with which the health care system is changing. The geometric growth of public and private managed care has taken center stage for many health advocates who work to find the most effective ways of representing the patient, the family and the health care consumer in this complicated area. The questions of access, cost and quality that are bottom line concerns in health care are at the forefront of an incredibly wide range of health advocacy work. Students still enter the program with very diverse backgrounds (our current student body includes nurses, primary care physicians, a sociologist, a social worker, recent college graduates, a number of people from the business world, a teacher, and so on). They use their placements to experience areas of advocacy that range from a bioethics program in a hospital to the inspector general's office (see our web site www.slc.edu for examples of recent field placements). And these days they leave in order to serve patients directly through counseling, support, mediation, education and other advocacy work with individuals and families, and indirectly through formulating, implementing or enforcing programs and policy.

The challenge of a graduate health advocacy program today is to educate professionals for a world of advocacy that encompasses so many arenas. In the HAP we need to become integrally connected to those various arenas: to bring them into the program; to serve them outside the program; and, most important, to ensure that graduates are equipped with the knowledge and skills to be professional health advocates, no matter in what arena they choose to work. These are some of the steps the Program is taking to move in these directions:

1. Changing the content and focus of HAII. The core work of the health advocate has always been taught in the second health advocacy course (HAII), usually following the exploration of the role of the advocate in HAI. When health advocacy was synonymous with patient representation, HAII could focus on the work of the advocate in the hospital, and function as well as to integrate fieldwork—hospital placements—with classroom learning. In order to have HAII continue to introduce students to the work of the health advocate, the course now needs to reflect the wide range of positions held by professionals in the field. Accordingly, a team of graduates, all advocates in different healthcare arenas, will be teaching HAII. They will use a number of guest professionals to help them explore four broad worlds of advocacy: direct service advocacy in provider institutions including hospitals, long term care facilities, and so forth; community-based direct service advocacy; advocacy work in the largely not-for-profit interest group and public interest world; and government-based health advocacy. This course will pilot in the spring. Descriptions of the new course and the faculty should be found on our web site.

> *"The challenge is to educate for a world that encompasses so many arenas."*

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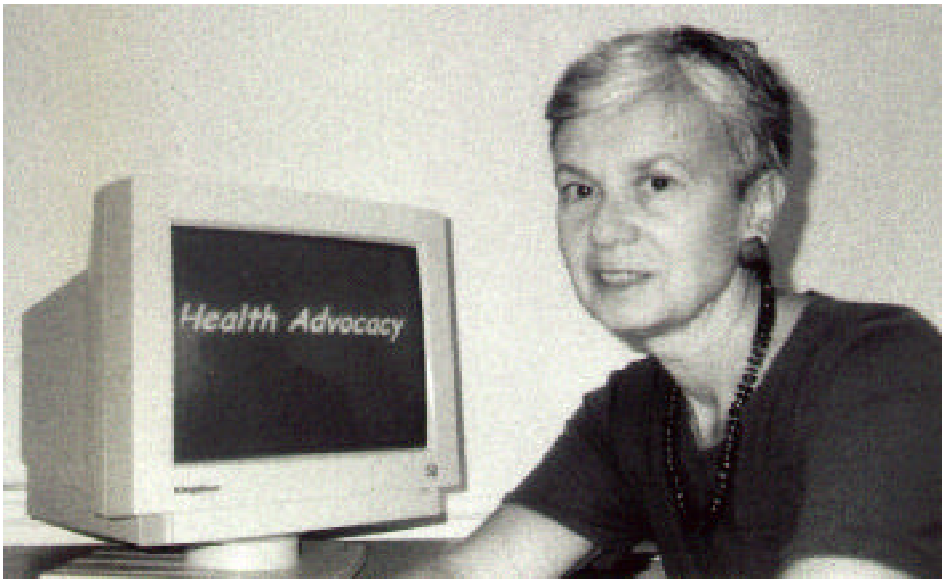
2. Continue building on program outreach. As health advocacy has moved to the forefront of concern locally as well as around the country, it has become increasingly important to connect with individuals and organizations who are advocates. I am working with the national and state Societies of Healthcare Consumer Advocacy, attending meetings and public forums on health advocacy issues, corresponding (email of course) with advocates in other parts of the country who are developing advocacy programs, and becoming part of local advocacy networks. I have been contacted by a number of organizations about working with themÑ from providing interns to developing programs. Whenever possible we are trying to get the Sarah Lawrence program Òout thereÓ in the world of people interested in health advocacy, and are using a range of media to do this. The WWW is an enormous resource. A wide range of consumers and advocates use the ÒlinksÓ section Deborah Hornstra developed for our web site. People interested in becoming health advocates find us on the web, and we are hoping to develop a web site that is even more useful to the advocacy community. This would include listing events, speakers, meetings not only on campus but also in the area that might be of interest to advocates, and providing a discussion forum for advocacy issues. (Perhaps on-line discussion would be a way to have that Journal Club I always wanted.) We hope that active advocacy in many forms will become an integral part of the HAP program.

3. Developing an interdisciplinary intellectual base at Sarah Lawrence. The graduate, and to some extent undergraduate, departments right at home provide a wealth of opportunities for enriching the academic core of our advocacy work. Most obvious, and perhaps most exciting, is the potential for collaboration with our partner health program, the Human Genetics Program (HGP). As a result of the phenomenal growth in genetics knowledgeÑ and the prospect of exponential growth in that knowledge through the stepped up pace of the human genome projectÑ the interface between advocacy and genetics has become critically important. Some of our students and graduates have already been working in this area with the March of Dimes. A current student is



pursuing a combined advocacy and genetics graduate study program. We are beginning to work together with HGP and the WomenÕs History Program, to become part of the National Council for Research on Women, with a Sarah Lawrence focus on advocacy, genetics and gender. Alice Herb (who teaches the HAP ethics course) and I are hoping to bring some ethicists to Sarah Lawrence for a special workshop this spring. A group of graduate program directors including the Early Childhood and Art of Teaching programs is also meeting to consider academic support we can give to Òzero to threeÓ childhood multi-service initiative in Yonkers.

4. Ensuring skills proficiency. HAP is also taking a look at what concrete skills graduates need. I am running a series of informal tutorials on computer skills, using the wonderful new computer classroom in the library. All health advocacy students now quickly learn to use the Internet for researchÑ and for advocacy. Our goal is that by graduation, they will also have familiarity with basic applications: word processing, spreadsheets, and presentation software, database structure and use, statistical software (SPSS). In addition, we are developing a list of other areas in which HAP would provide training, including grant-writing, budgeting, JCAHO familiarity, career development skills and so forth. If there are any particular skills you have found essential to your work as advocates, please let me know.

5. The Strategic Planning Committee. There is a great deal of other work we are hoping to accomplish in HAP. SomeÑ like developing a health advocacy resource centerÑ involve ideas that have been floating around for a while and we are beginning to actually implement. OthersÑ like responding to the need expressed in the larger advocacy community for additional models of health advocacy education, e.g., distance learning, graduate level certificate programs, short intensive immersion coursesÑ involve responding to a more recent need. The newly formed Strategic Planning Committee composed of students, faculty, Advisory Board members, alumnae and myself has begun meeting to consider short and long term goals and objectives for the program as a whole. Whether or not you are alumnae, tell us what kind of advocacy work you are doing, what issues you face, and how HAP can be responsive to the needs of this growing profession.

I plan to use the forums of the Web site and this Bulletin to keep you informed about the Health Advocacy Program.

In honor of the end of a very wonderful baseball season (even for an old Red Sox fan) I will indulge in one more Yogi Berra quote, this one particularly apt for our Strategic Planning efforts:

"You got to be very careful if you don't know where you're going, because you might not get there. "

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