

CITIZEN VOICES

in HEALTH ETHICS



A Newsletter of the New York Citizens' Committee on Health Care Decisions Inc.

Winter 2006

JOSEPH J. FINS, MD, FEATURED SPEAKER AT ANNUAL MEMBERS' RECEPTION ON JUNE 22, 2006



Dr. Joseph Fins

Members and guests attending the annual reception were rewarded with Dr. Fins' presentation on "The Challenge of Brain Injury: Neuroethics After Schiavo". Starting with a recap of recent court decisions illustrating the trends in autonomy, Dr. Fins went on to further explore the ethical and practical challenges in

treating the brain injured. His presentation drew from his long experience with hands-on ethics consultations.

Much of the public distress and political stir over the Schiavo case represented issues that had been addressed before. The Cruzan and Quinlan cases addressed autonomy, decision making, and the right to die... but with an emphasis on ventilatory support and artificial feeding. Confusion over the meaning and implications of brain injury drew the attention of the public, press, and politicians. He was able to explain the turmoil around the Schiavo decision through the public's confusion of the meaning of persistent vegetative state.

Terry Schiavo was contrasted with another Teri – Teri Wallis, a man who recovered cognitive function after several years of apparent coma. Dr. Fins went on to explain the different levels of consciousness; how they are defined, the likelihood of recovery and the challenge of separating out those who may resume some function. Different from Schiavo in many ways, type and extent of brain damage, the Wallis case begs for more exploration

into the nature of brain damage. Unknown numbers of minimally conscious subjects, almost all in nursing or private homes, may benefit from greater attention.

Joseph J. Fins, M.D., F.A.C.P. is Chief of the Division of Medical Ethics at Weill Medical College of Cornell University where he serves as Professor of Medicine, Professor of Public Health and Professor of Medicine in Psychiatry. In addition, Dr. Fins is Director of Medical Ethics at New York-Presbyterian Weill Cornell Medical Center and a member of the Adjunct Faculty of Rockefeller University. He has served as Associate for Medicine at The Hastings Center and been a Visiting Professor in Medical Ethics at The Complutense University in Madrid. He is a recipient of a Soros Open Society Institute Project on Death in America Faculty Scholars Award and a Woodrow Wilson National Fellowship Foundation Visiting Fellowship. In July 2000, Dr. Fins was appointed by President Clinton to the White House Commission on Complementary and Alternative Medicine Policy.

A diplomat of the American Board of Internal Medicine, Dr. Fins is a graduate of Wesleyan University (B.A. with Departmental Honors, The College of Letters, 1982) and Cornell University Medical College (M.D., 1986). He completed his residency in Internal Medicine and Fellowship in General Internal Medicine at The New York Hospital-Cornell Medical Center.

A practicing internist at New York Presbyterian-Weill Cornell Medical Center, Dr. Fins chairs the hospital's ethics committee and teaches medicine and clinical ethics to Cornell medical students and house staff. He is the

(Continued on page 2)

(Continued from page 1)

author of over one hundred fifty publications in medical ethics and health policy. His most recent book is *A Palliative Ethic of Care: Clinical Wisdom at Life's End* published by Jones and Bartlett. His current scholarly interests include ethical issues in brain injury and disorders of consciousness, palliative care, research ethics in neurology and psychiatry, medical education and methods of ethics case consultation. Dr. Fins has lectured widely in the United States, Europe and Latin America and has been honored to give named lectures here and abroad.

Dr. Fins is Governor-Elect of the American College of Physicians (New York Downstate Region) and serves on the Board of Trustees of Wesleyan University, the Fund for Modern Courts, the National Advisory Committee of The Woodrow Wilson National Fellowship Foundation and the Board of Directors of the American Society of Bioethics and Humanities. He is a member of the Editorial Boards of the *Journal of Pain and Symptom Management*, *The Cambridge Quarterly of Healthcare Ethics* and *The Oncologist*.

Dr. Fins is a Fellow of the American College of Physicians and the New York Academy of Medicine and the recipient of a Health Advocacy Award of the New York Society of Patient Representatives and the Wholeness of Life Award of the HealthCare Chaplaincy. Dr. Fins served on Mayor-Elect Rudolph Giuliani's Transition Team Health Care Advisory Group and has been a consultant to the Pan American and World Health Organizations. From 1997-1998, Dr. Fins served on the New York State Attorney General's Commission on Quality Care at the End of Life.

Portions of Dr. Fins presentation can be found <http://www.tbi-interagency.org>. (look under "Translating Emerging Knowledge....")

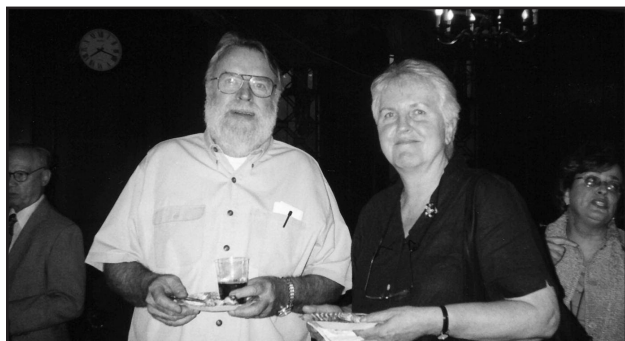
Annual Members' Reception • June 22, 2006



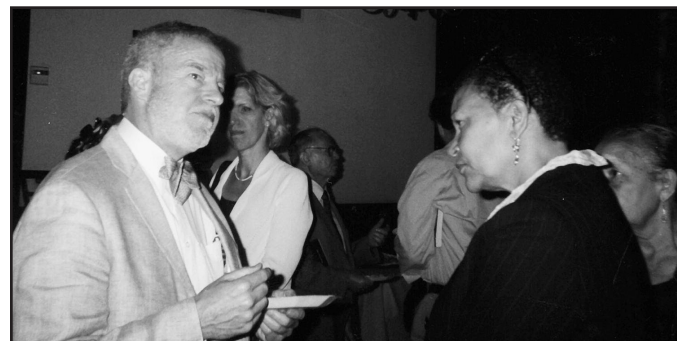
Dr. Joseph Fins addresses audience at the Annual Members' Reception, June 2006.



Annual Members' Reception, June 22, 2006.



Past NYCCHCD Board Member Mary Meyer and husband, Karl Garlid.



NYCCHCD Board Members Dr. John Cornwall and Rosa Rosen.

BOOK REVIEW

A PALLIATIVE ETHIC OF CARE: CLINICAL WISDOM AT LIFE'S END

By Joseph J. Fins. 281 pp. Sudbury, Mass., Jones and Bartlett, 2006. \$39.95. ISBN 0-7637-3292-3.

“A Palliative Ethic Of Care: Clinical Wisdom at Life’s End” can be reviewed at <http://www.jbpub.com/catalog/0763732923/>

“ ‘If there were a silver lining about the physician-assisted suicide debate, it was that this tension helped catalyze the palliative care movement.’ So writes Joseph Fins in *A Palliative Ethic of Care*. This book is for physicians, nurses, and all others who care for those with life-limiting illnesses.... *A Palliative Ethic of Care* is well worth reading, even by veteran clinicians....”

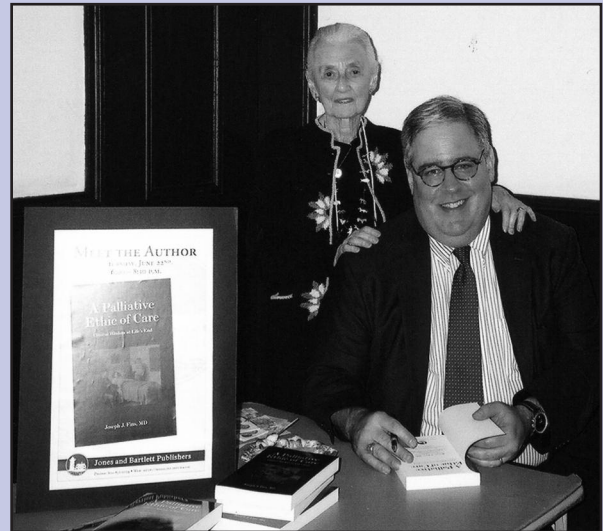
Mellar P. Davis, The New England Journal of Medicine, Vol. 354, Issue 15, April 2006.

“In a refreshing change from many ethics texts, this conversational style makes the book accessible and very readable....The value of Fins’ experience in performing ethics consults over many years shines through..... I really felt I was learning from a master craftsman.”

James Hallenbeck, The Oncologist 2006, Vol. 11, #5, May 2006.

“... Dr. Fins’ book, *A Palliative Ethic of Care: Clinical Wisdom at Life’s End*, reframes the challenge of caring for dying patients with a pragmatic approach grounded in the philosophy of palliative care. The intention of this book is simple – to improve the care of dying patients and their families.... The strength of the book lies in its easy-to-read, logical structure..... I would expect this book to become a required read for medical students”

Craig D. Blinderman, Journal of Pain and Symptom Management, Vol. 31, No. 5 May 2006.



NYCCHCD Chairperson Beatrice Greenbaum at book signing with Dr. Joseph Fins.

ROSA ROSEN NAMED TO NYCCHCD BOARD

We welcome Rosa Rosen, JD, to the Board of Directors of NYCCHCD. Ms. Rosen was born in the Dominican Republic and has lived in New York City since 1982. She graduated from CUNY, receiving a BA degree from the Center for Urban Legal Studies followed by a JD degree from the Hofstra University School of Law. Since being diagnosed with diabetes in 1997, Ms. Rosen has become a diabetes advocate and educator. Currently, she is Director of Diabetes Education & Training for the NYC Department of Health and Mental Hygiene.

GREETINGS FROM THE CHAIR ...

Once again as “Autumn Leaves Begin to Fall”, and busloads of tourists are “ooh-ing and ah-ing” at the dramatic spectacle of fall foliage unfolding in a blaze of splendor, back home in “Concrete City” we too are indulging in an annual ritual, albeit one of a slightly varied genre.

To wit, a series of “Déjà vu All Over Again” speculative musings, “Can NYCCHCD this small but vibrant grassroots initiative be sprouting roots of an emerging life of its own?”

A long arm’s reach? A flight of fancy? An over-active imagination? All or none, or perhaps a simplistically justifiable premise given its history from Day One to Now.

Conceived to establish a viable entity promoting an impartial forum for public discussion of critical health care and bioethics issues, NYCCHCD has achieved its goal – and then some.

In spawning a challenging environment empowering a newly informed activated citizenry to spout the core tenets of Advance Care Planning for Medical Care Decisions while freely “ticking off” the glossary of technical terms – the Living Will, NY State Health Care Proxy Law, Hospice and Palliative Care, Doctor-Patient Relationship, DNR, CPR, Informed Consent, all bulwarks of the foundation for end-of-life Medical Care-mastered attending NYCCHCD’s Community Outreach Education Program.

A most recent upsurge in the Speakers Bureau Activity Agenda is a case in point. Responding to the desperate often disparate community problems, it has nurtured a flourishing potpourri of problem-solving promising something for everyone: personalized issue-centered workshops for both the deaf and blind population; presentations targeting geographic localities with emerging enclaves of diversified ethnic, faith-based, cultural history and values as newcomers and neighbors; the perpetually increasing frailties of the underserved, ever-needy aging and the severely compromised physically, emotionally, socially and financially-deprived among us.

One has but to scan this current issue of Citizens Voices to recognize the distinctive essence of NYCCHCD. Reflected in its articles, personalized tin-types, photos and reviews of past and upcoming events are the external influences of a shifting political, social and cultural climate affecting both its organizational framework and emotional persona when internalized.

Featured in its Activity Summary, the bi-seasonal “Let’s Talk” series, an open forum stimulating inter-active exchange of a wide range informational, often confrontational issues, is capped by the Spring Members Reception focusing on a front-page medical, bioethical legal headliner, starring a “name” speaker attracting and galvanizing an enthusiastic compatible professional and lay community responsive audience.

A recent spurt of collaborative alliances with the Caring Coalition of Metro New York, HEAL (Healthy Ethics Action Leadership) sponsored by the Center of Aging and Social Work Department at the CW Post Long Island University Nassau County Campus, and NYCCHCD’s Round Table Discussion Session “Deaf Project” at the American Public Health Organization’s Annual Meeting on November 8, 2006, further attests to the many doors opened to and entered by NYCCHCD.

(Continued on page 5)

(Continued from page 4)

Not invincible to the mood swings of joy, pride and sorrow, served up by its portion of the “slice of life”, NYCCHCD notes with joy Dr. Monair Hamilton’s lead article featured on these pages. Clear and Convincing Evidence in testimony of the forces of perseverance on her rapid ascent up academia’s success ladder. Following her 2-year stint as NYCCHCD’s Program Administrator, while pursuing an MPH at the Hunter College evening program, on to a fellowship at Kent State University — PhD, goal achieved in December 2005, and now a tenured college professor. How about that?

Congratulations with enormous pride to Loretta Goff, earliest Speakers Bureau trainee, dedicated, accomplished, much in demand “frequent flyer” for her spectacular achievement award and the first Speakers Bureau volunteer to be highlighted in our newsletter. Her innovative approach to Advance Care Planning outreach holds great promise for NYCCHCD’s future.

Turning the page to yet another view of this emotional spectrum, we mourn with deep sadness the death of Mary Strong – the immeasurable loss and emptiness of life without her – only partially filled by the richness of her legacy – the gift of life – to NYCCHCD from the New Jersey visionary who as its mentor spearheaded the founding of its New York counterpart, infused by the beauty of her spirit, never to be forgotten – always hailed with love and appreciation – a Friend Always In All Ways!

Little wonder then, all things considered, strong forceful vibrations might conceivably inject life into a readily susceptible entity, whose history and performance could well-provide credentialing for Personhood – Be It Veritable Or Virtual.

Who’s to know, and must we?

Which ever way the NYCCHCD chooses to sustain its viability for a projected healthy future, it will continue to look to you, its immediate family of members, while welcoming an extended family of friends and neighbors to bring to the table the basic nutrients for growth, strength and the spice of life.

As always, we invite you to join us as we go forward, enjoying the fruits of our continuing relationship.

Thank you,



Beatrice Greenbaum

BECOME A MEMBER

For only \$35 a year or \$60 per couple (*\$100 for institutions*) you can support the non-partisan community outreach work NYCCHCD performs every day of the year and receive our newsletters, mailings and invitations to our events.

Please call **212-586-4638**

PHYSICAL ACTIVITY PATTERNS OF AFRICAN-AMERICAN WOMEN:

A REFLECTION OF OUR YOUTH



Dr. Monair J. Hamilton

With the publication of *Healthy People 2010: Understanding and Improving Health*¹, American's public health agenda for the next decade was defined. As part of this national strategy, baseline data were provided and objectives specified for promoting health, reducing preventable death and disability, and enhancing the quality of life for all. In related research, McGinnis and Foege² investigated morbidity and mortality by contrasting the clinical diagnosis of patients at the time of death with the root cause of their death. Importantly, McGinnis and Foege reinforced the contribution of individual behaviors to premature death and disability among Americans.

In a follow-up study published in 2004³, Mokdad, Marks, Stroup and Gerberding re-examined the work of McGinnis and Foege (1993)² and compiled current epidemiological, clinical, and laboratory studies with particular focus on the contribution of various factors to U.S. mortality. This update revealed that close to half of all deaths among Americans result from preventable behaviors and exposures to unhealthful substances.³ Moreover, this analysis revealed one important change not in evidence at the time of the earlier work conducted by McGinnis and Foege (1993).² Specifically, although McGinnis and Foege estimated that 300,000 deaths per year were caused by poor diets and physical inactivity, Mokdad et al.³ estimated that 400,000 deaths are now attributable to these particular behaviors. This represents an increase of deaths specifically related to diet and inactivity and is the largest increase among all actual causes of death.³ Although specific analytical approaches differed between the work of McGinnis and Foege and that of Mokdad et al., it was concluded that poor diet and physical inactivity, along with alcohol and tobacco use, account for a substantial proportion of preventable deaths in the United States.³

Recently, the calculations in the findings published by Mokdad, Marks, Stroup, and Gerberding (2005)⁴ were corrected in the *Journal of the American Medical Association*. Although the conclusion remains unchanged, that poor diet and physical inactivity account for a substantial proportion of preventable deaths in the United States, it was important to clarify the potential double-count of deaths attributed to these specific behaviors.⁴

Research has confirmed that the number of overweight Americans has increased across all segments of the population.^{1,5,6} MacKay, Fingerhut, and Duran⁷ asserted that individuals who begin participating in a physically active lifestyle during adolescence are more likely to continue this behavior pattern through adulthood. In this context, literature in health education confirms that behaviors affecting all areas of persons' character and personality are cultivated during childhood and follow individuals through adulthood.^{1,7,8}

In a report published in the *New England Journal of Medicine*, Kimm et al.⁹ revealed that the majority of adolescent females within the United States manifest steep declines in physical activity. Physical inactivity is a major contributor to this growing and dangerous trend among young African-American females, "with black girls having a decline in activity twice that of white girls".⁹ The study conducted by the National Heart, Lung and Blood Institute Growth and Health Study (NHLBI) researchers followed 1,213 Black girls and 1,166 White girls between the ages of 9 or 10 through the ages of 18 or 19 to assess activities during recreation, sports, leisure time, and physical-education classes during school hours. The subjects were from schools and health maintenance organizations in San Francisco, Cincinnati, and Washington, D.C. Results of the study revealed that the rates of physical activity declined precipitously among adolescent girls as they got older. In fact, by the ages of 18 or 19 the majority of study subjects did not engage in any regular physical activity outside of school.⁹ This study revealed that among all the adolescent female participants in the study, heavier girls, regardless of race, reflected a significantly lower level of physical activity than girls who were not as heavy. This research did confirm however that the subject's race was significant as Black girls exhibited declines in physical activity participation twice that of their White counterparts.⁹

(Continued on page 7)

(Continued from page 6)

Former Surgeon General Satcher has reinforced the urgency of recognizing obesity and overweight as critical public health problems in the United States. *The Surgeon General's Call to Action To Prevent and Decrease Overweight and Obesity*¹⁰ published by the Public Health Service, confirms that overweight and obesity among Americans is, in part, associated with unhealthy eating habits and irregular physical activity.¹⁰ This report asserted that communities partially are to blame. According to the Surgeon General, “When there are no safe, accessible places for children to play or adults to walk, jog, or ride a bike, that is a community responsibility”.¹⁰



Non-modifiable characteristics, like age, sex, and race, are of particular concern to health promotion professionals. This concern is heightened due to the implication of disparity among selected groups, specifically minority groups who have been historically disenfranchised. Traditionally race has been used as a convenient label to examine diseases and chronic illnesses in multiracial societies as in the United States.¹¹ A justification for racial differences as a category would be better served by classifying race as reflecting different social environments. “Race does not mark in any important way for genetic traits; rather, it demonstrates beyond question the paramount role of the social causes”.¹¹

In the early 1990s, Covey and Feltz¹² studied patterns of physical activity among adolescents. A major finding of their study was that many adolescent high school girls self-reported on the instrument as being physically active. It was believed at the time that either it was socially desirable to be physically active or at least socially desirable to report being physically active on the survey in high school.¹² Those high school girls identifying themselves as reporting a decreased physical activity level also reported this decrease as due to a “lack of time and the demands of other important activities in their lives, such as jobs, schoolwork, chores, etc.”¹² This psychosocial influence over physical activity reflected that even as early as adolescence, these girls have to make hard choices between activities that are seemingly more important such as homework and other responsibilities and are not focusing on opportunities to participate in physical activity.¹²

Research also indicated, “Positive attitudes toward health behavior are more likely to lead to higher levels of readiness to engage in activity, self-efficacious judgments of one’s ability to engage in positive health behavior, and acquisition of higher levels of disease risk awareness”.¹³ This point about positive attitudes is important as the literature reveals that health behaviors in childhood and adolescence can translate into lifelong health-enhancing behaviors; positive attitudes will encourage adolescents to engage in physical activity. Dismissing adolescent challenges in overcoming barriers of psychosocial influences over physical activity is not the best strategy in helping them make positive strides towards a healthier lifestyle.

Immediate family members such as mother/grandmother, sister/brother influenced the body size of Black participants in a study focused on body image. Similarly, Black females were influenced by family members, as well as authority figures with which those Black females were in regular contact, such as teachers and administrators. “These results suggest Black adolescents are influenced more by adult role models in terms of body size preference development”.¹⁴ This information suggests to “successfully reach black female adolescents, role models from their families and community must be identified. This can be a challenge, as the culture of obesity tolerance may provide mostly role models who themselves are overweight or obese”.⁸

Psychosocial influences among Blacks include education. Among African American women who were at least high school educated, as their age increased, their walking for leisure and engaging in moderate activity increased. As age increased, strenuous activity participation decreased markedly, especially with women aged 60-69.¹⁵ Studies have also confirmed that non-Hispanic Blacks are less likely to participate in leisure time physical activity than non-Hispanic Whites and Mexican Americans. But this group reflects higher levels of occupational activity. When it comes to employment African-Americans are more likely to work in blue-collar jobs.¹⁶

(Continued on page 8)

(Continued from page 7)



Family variables also play a part in physical inactivity among women. “Barriers to physical exercise for middle- to older-aged African American women may include time constraints, multiple roles (e.g., financial provider, mother, caretaker) and role conflict, often due to the burden of work and other responsibilities”.¹³ Women reporting membership in social organizations were more likely to have decreased opportunity to be physically active.¹⁸ Many African American women have low paying jobs with few benefits and limited or no retirement income. This makes them less likely to be able to afford opportunities for health promotion, including information, resources, or additional time in their day for physical activity. Women in their middle to older years are more likely to have the added responsibility for intergenerational care-giving (i.e., younger children, grown children, and elderly parents), reflecting once again the barriers and reasons for physical inactivity among Black women.¹³

Empirical evidence reveals that diet is an influencing factor contributing to the overall physical inactivity among racial and ethnic groups. The extent to which diet influences activity levels can stretch beyond the obvious economic barriers to a myriad of cultural issues impacting these groups. Social variables that may influence diet consumption and activity levels could include the economic element of the cost of healthy food from the local supermarket.¹⁷

Levels of attractiveness also seem to play a role in African American women’s lack of physical activity. Studies have shown that the higher the socioeconomic status, the more committed to the ideal of slimness among Black women. But Black men do not seem to consider a woman’s weight as a deterrent when it comes to dating. So for Black women, higher body weights may play a role in attractiveness and reinforce the tolerance for wide parameters in body sizes.⁸ Perceived attractiveness seems to play a role in African American women’s lack of physical activity. Studies have shown that the higher the socioeconomic status of Black women, the more committed to the ideal of slimness. Socialization between men and women is important in the Black community. Black men focus on women’s weight as a deterrent when it comes to dating. So for Black women, higher body weights may play a role in attractiveness and reinforce for wide parameters in body sizes. Physical activity would then be a disincentive for socialization among Black women, as a larger size woman continues to be attractive to the opposite sex.^{8,19,20,21}

A review of the current literature reveals that there is evidence to support a lack of physical activity among African-American adolescent girls. Among adolescents, physical inactivity is the strongest predictor of becoming overweight, and heavier young people experience health problems including Type 2 diabetes, high blood pressure, sleep apnea, and gall bladder diseases. These health problems previously seen in adults are now prevalent among adolescents. Utilizing this information alone, it is difficult not to support the Surgeon General in calling this health problem a public health crisis as adult illnesses are manifesting in children. African-American adolescent young women are emerging as being at significantly higher risk due to factors compounded by race and ethnicity. Social support, positive role models, and opportunity for physical activity can motivate youth to action.¹ Serious efforts are being made to develop culturally sensitive and developmentally appropriate physical activity programs. Programs tailored to promote positive attitudes and appreciation towards engaging in physically active health-enhancing behaviors can change the trends of sedentary lifestyles.

Monair J. Hamilton, PhD, MPH, CHES, is assistant professor, Department of Health, Physical Education, and Recreation, Coastal Carolina University. For references please email to: mjhamilt@coastal.edu.

OUR MISSION

The New York Citizens’ Committee on Health Care Decisions is a non-profit, non-partisan grassroots initiative providing an impartial forum for public discussion of critical health care issues.

NYCCHCD "LET'S TALK" SERIES

Fall 2005

October, 20, 2005

Palliative Care: Here, There and Everywhere – Hospital, Hospice, Homecare.

Madeline Jacobs, MPA *Senior Project Manager, Palliative Care Initiatives, Metropolitan Jewish Health System*; Jeffrey Nichols, MD *Assistant Medical Director, Cabrini Hospice*; Eugenia Siegler, MD *Medical Director, Geriatrics Inpatient Service, Cornell Campus/New York Presbyterian Hospital.*



*Let's Talk Fall 2005 guests:
Mr. and Mrs. Farley with Chairperson
Beatrice Greenbaum*



Let's Talk Fall 2005, audience

December 1, 2005

Mediation in End-of-Life Care:

A New Paradigm for Resolving Medical Care Conflict.
Mark Goodwin, Esq., Montefiore Medical Center.

SPRING 2006

May 11, 2006

**Open Forum: Voice Your Concerns,
Our Interdisciplinary Panel Will Address Them.**

Social Worker: Nancy Avitabile, LMSW, CMC, Montefiore Medical Center; *Doctor:* John Cornwall, MD; *Lawyer:* Mark Goodwin, Esq.; *Bioethicist:* Joel Roselin, MTS, National Center for Ethics, Veterans Health Administration.



*Let's Talk Spring 2006 Panel:
l. to r. Board Member Dr. John Cornwall, Nancy Avitabile, and
Board Members Joel Roselin and Mark Goodwin.*



*Let's Talk Spring 2006 Panel:
l. to r. Board Members Dr. John Cornwall and Mark Goodwin,
and David Bershod.*

March 23, 2006

Medicare Part D:

Personalizing Your Prescription Drug Plan.

Amy Bernstein, NYC Department For The Aging
David Bershod, Town Total Nutrition,
John Cornwall, MD.

REMEMBERING MARY JOHNSTON SUTHERLAND STRONG FEBRUARY 18, 1924 – FEBRUARY 26, 2006

In sharing the sadness of Mary Strong's death, we reap the joy of remembering and celebrating the gift of Mary's life – a life beautifully wrapped and tied with multi-colored bows and streamers reflecting her self-styled classic demeanor and the beauty of soul, spirit and mind.

Mary's dying, while anticipated, carried with it the sting of finality, difficult to accept. Simply put, "We may think we are prepared, but we are never ready."

Each of us, in our own way, in time of grief reaches out for solace and comforting. In some strange and wondrous way — call it "Mary's way" — she herself has provided each of us with the special gift of ultimate consolation.

In keeping with her philosophy of end-of-life care underlying her life's work, Mary's acceptance of the terminal prognosis of her illness, her choice of non-aggressive palliative hospice care replete with its Joy and Hope, neither a misnomer nor an oxymoron, and the grace with which she managed living while dying, was Mary to the core.

For all who knew and loved Mary who were there with her in self or in spirit during her last weeks, what more precious legacy of love could she have bequeathed them other than to know that pain-free, alert and at rest, Mary spent her final days in peace!

When asked by her family to reach those of Mary's bioethicist colleagues known to me, I felt privileged then as I do now. For them, her extended family, it offered the opportunity to express their thanks and pay tribute to Mary for her gift to their lives.

For me, a bittersweet assignment with visions of tears amidst smiles — one never to be forgotten – one to be cherished always!

Their responses were predictable! As if with one voice came an outpouring of sadness mingled with praise, devotion, love and reverence — literally a personal autobiography of each one's treasured relationship with Mary — mover and shaker, innovator, leader and mentor, who saw the light early on and lit the path for others to follow in her footsteps.

In alerting both the private and public sectors to the dire need for state-by-state legislation for Advance Care planning for End-of-Life Decisions, Mary the woman of all seasons for all reasons – emerged as Mary Making History! Then as now she clearly could have served as the ultimate role model for the Ladies Home Journal's slogan "Never Underestimate the Power of a Woman".

A picture of composure — adept at dealing with life's daily changing agenda – a self-starter responding to her own drive 'to be someone' and to 'do something' special with her life while serving others – Mary the quick-study volunteer with the United Nations non-governmental organizations (NGO's) in short order became Mary, the Visionary cum Activist instinctively geared to turn Dreams into Reality, Need into Action.

Aided by a small group of like-minded volunteers, Mary's infectious passion jump-started the creation of New Jersey Health Decisions. Swiftly rising to the top rung of America Health Decisions ladder, as co-founder and chairperson, she soon reached out to the sister-state across the Hudson – as convener of selected steering committee. Presto – the birth of NYCCHCD with Mary sitting proudly as the special honored member of its Board of Directors.

Mary's death has left a huge vacuum in the special lives of so many, as in mine – never to be refilled. We were truly kindred spirits, amazingly in touch with each other's thoughts and needs. It was her decision to place me at the helm of the newly launched New York organization adding a new dimension to my Public Health, Hospice and Patient Advocacy life. I did her bidding – who could refuse her and have never regretted it. The thread which had been tied and double-knotted became a lasting bond between us – growing stronger and even more elastic with time.

The move to Fox Hill provided Mary with a new brand of on-site venues for expanding her mission. Quick to spot a community poised to delve deeper into the everyday challenges to maintain control over one's end-of-life care, Mary brought a wealth of knowledge and hands-on "know-how" and experience with creative program, seminars, work-shops featuring Advance Care Planning for Medical Care Decisions. Sensitive to this diversified population with a wide range of cultural, ethical, moral political and religious mores and beliefs, Mary's last project will become institutionalized in her name.

(Continued on page 11)

(Continued from page 10)

During these later years, our energy personalized a shift to the realities and myths of living in the world of octogenarians. We burned the telephone wires at both ends with a steady barrage of exchanging thoughts and experiences, bemoaning the social and medical inroads while reveling in the perks of the aging – particularly the freedom to say what we mean, and mean what we say – throwing caution to the winds as the spirit moved us.

My in-person visits to Mary and subsequent telephone visits during her final days were not overshadowed by the “hovering inevitable”. Rather, apart from their bedside ambiance they were a normal mixture of a serious review of the professional world we knew, and frivolous often irreverent recollections of our uniquely dubbed stature as the Bobbsey Twins at National Bioethics Meetings. Mary shared memories, much introspection, no regrets!

Our very last calls were silent expressions of deeply emotionally-charged parting and love – letting go as the prelude to the last sleep – The final goodbye unsaid but not unfelt – an indelible stamp which will never fade. My constant thanks to Mary for having enriched my life.

Mary died as she lived – pain-free with family at her bedside, peacefully prepared to leave.

In remembering the spirit of Mary – as we go forward without her – she will always be deeply missed but be assured that she will be always at our side!

Excerpted from the eulogy at the service of Mary Strong on Saturday, April 8, 2006. First Parish of Westwood, United Church, Westwood, MA.

Volunteer Profile

As an outreach-related not-for-profit, NYCCHCD is only as effective as our volunteers are dedicated, and we are very fortunate to have such a well-trained, sincere and hard-working volunteer corps in our Speakers Bureau. They are deserving of our thanks and admiration, and we feel our members should know more about these stellar individuals who make NYCCHCD what it is. We are pleased to launch this new section of Citizens' Voices highlighting our volunteers.



Loretta Goff is a Registered Nurse with a BS in Health Care Administration, a MS in Community Mental Health Counseling and extensive experience with the New York State Office of Mental Hygiene and Office of Mental Retardation and Developmental Disabilities as a Nurse and Treatment Team Leader. In 2003, she retired from the New York State Commission on Quality of Care for the Mentally Disabled after 25 years of service as a Protection and Advocacy Specialist, where she provided oversight and advocacy for individuals with disabilities in New York State.

Since her “retirement”, Ms. Goff has increased her involvement in civic and community activities. In addition to being a NYCCHCD Speakers Bureau Volunteer, she is a trained Hospice Volunteer, a Parent Educator for incarcerated women at a NYS Correctional Facility, and continues to be an advocate for individuals with disabilities in the United States. She most recently received a four year Senate appointment to the Ticket to Work and Work Incentives Improvement Act Advisory Panel. This panel is charged with advising the President, Congress and Commissioner of Social Security on issues related to work incentive programs, planning and assistance for individuals with disabilities and The Ticket to Work and Self-Sufficiency Program established under this act. Additionally, Ms. Goff has been appointed to the New York State Protection and Advocacy for Individuals with Mental Illness Advisory Board.

Ms. Goff is very active in the life of her church, Jackson Memorial African Methodist Episcopal Zion Church in Hempstead and is a member of Delta Sigma Theta Sorority, Inc, Nassau Alumnae Chapter.

BOARD OF DIRECTORS

Chairperson

Beatrice W. Greenbaum, M.P.H.

Vice-Chair

John W. Cornwall, M.D.

Secretary

Mark D. Goodwin, J.D., M.S.W.

Treasurer

Sara R. Faison

Directors

Bry Benjamin, M.D.

Carmelita Blake, Ed.D.

John Evangelista M.D., M.P.H.

T. Patrick Hill, Ph.D.

Jay Kantor, Ph.D.

Judith Lauterstein, Ph.D.

Sandra E. Mager

Paula Maresca, R.N.

Joel M. Roselin, M.T.S.

Rosa Rosen, J.D.

Beverly L. Sloane

SAVE THESE DATES!

LET'S TALK - FALL 2006

Where There's A Will - There's A Way

Four Paths

Living Will - Testamentary Will - Ethical Will - Halachic Will

An In-Depth Exploration To Find "Your Way"

Thursday, October 26, 2006

Caring Coalition of Metro New York

Health Care Proxy Weekend

November 10-12, 2006

LET'S TALK - SPRING 2007

An Epidemic of 2006 - A Threesome Scourge

Diabetes - Hypertension - Obesity

How Did It Happen? What Is The Effect? How To Combat It?

Thursday, March 29, 2007

Health Literacy

What You Need To Know

Thursday, April 26, 2007

Annual Members' Reception

Strachan Donelley, PhD, President and Bruce Jennings, MA, Director
Center for Humans and Nature

Thursday, May 31, 2007



NEW YORK CITIZENS' COMMITTEE ON HEALTH CARE DECISIONS

1775 Broadway, Suite 300

New York, New York 10019