

# CITIZEN VOICES

## in HEALTH ETHICS



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

Fall 2009



*Carol Levine*

### **“FAMILY CAREGIVING: NEW DEMANDS AND ETHICAL CHALLENGES” PRESENTED BY CAROL LEVINE AT JUNE 11, 2009 ANNUAL MEMBERS’ RECEPTION**

On Thursday, June 11, 2009, New York Citizens’ Committee on Health Care Decisions proudly welcomed Carol Levine as the guest speaker for our Annual Members’ Reception held at the New York Society for Ethical Culture. Ms. Levine’s highly comprehensive and detailed PowerPoint presentation, augmented by a most informative and inspiring lecture on “Family Caregiving: New Demands and Ethical Challenges,” was a glowing highlight in the overall spectrum of this year’s activity roster.

Carol Levine joined the United Hospital Fund - New York City in 1996. She is currently the Director of the Families and Health Care Project, which focuses on developing partnerships between health care professionals and family caregivers, especially focusing on the transitions in health care settings ([www.nextstepincare.org](http://www.nextstepincare.org)). She had previously directed the Citizens Commission on AIDS in New York City from 1987-91, and The Orphan Project from 1991-1996. As a senior staff associate of The Hastings Center, she edited the Hastings Center Report. In 1993, she was awarded a MacArthur Foundation Fellowship for her work in AIDS policy and ethics. She edited *Always On Call: When Illness Turns Families into Caregivers* (2nd ed., Vanderbilt University Press, 2004); and, with Thomas H. Murray, co-edited *The Cultures of Caregiving: Conflict and Common Ground Among Families, Health Professionals and Policy Makers* (John Hopkins University Press, 2004). And, as a “Can you top this?” commendation, she was named a WebMD Health Hero in 2007.

In meeting our expectations and beyond, Ms. Levine shared with the audience her 17-year-long personal experience as home-based caregiver for her husband who had become severely incapacitated due to a serious car accident. She relayed her frustrations with numerous facets of the present health care system and the endless complications with both private and public insurance coverage; the difficulties she encountered trying to navigate these two largely seemingly impersonal and uncaring systems; and the meaningful solutions she painstakingly wrought from her ongoing personal experience in this milieu. She offered professional guidance and much heartfelt, personal advice to members of the audience who raised question after question based on their own involvement in caring for a loved one at home.

All present were privy to a deeply moving and enlightening evening, as one audience member after another responded with wrenching testimonies of their own home caregiving experiences, deeply impelled and inspired by Carol Levine’s candid and moving portrayal of *Her Own Remarkable Journey*. The questions, comments and stories could easily have continued long into the night. We were indeed privileged and grateful to have had the gift of such a professionally knowledgeable and personally compassionate moderator to help guide us along in our exploration of the current home caregiving process. Thank you once again, Carol Levine! This evening was indeed but an introduction to an issue that will continue to touch us all on some personal level as we each move along on *Our Own Life’s Journey*.

## GREETINGS FROM THE CHAIR ...

Begging his pardon, we hereby take the liberty of borrowing from Lewis Carroll's Through the Looking Glass to quote a segment from his poem, entitled "The Walrus and the Carpenter:" ' ... The time has come,' the Walrus said, 'To talk of many things: Of shoes—and ships—and sealing wax—Of cabbages—and kings ...' And while our domain is neither one of cabbages nor kings, our "organizational" plate is always filled with tastefully-prepared programs and our domain, "Queenly" royal, given our unrelenting quest to fulfill the mission of our founder, Mary Strong, who would have grinned quizzically, yet approvingly, at the direction taken by her protégé.

This year has successfully brought us through organizational changes: Sara R. Faison, long-time Treasurer and devoted Board Member, has lightened her "Volunteer" load, yet not cut the strings that bind us; nor has Mary L. Meyer, who, by exchanging her scribe's pen, as Board Secretary, for a trowel, has found much satisfaction in an artistically-fulfilling career as garden designer. We thank them both for their years of dedicated service and Wish Them Well! As for the here and now, we continue to go forward in the most competent hands of Mark



*Mark D. Goodwin, JD, MSW  
NYCCHCD Board Secretary  
and Acting Treasurer*

Goodwin who has assumed the dual role of Secretary / Acting Treasurer – which prompts us to quizzically yet boastfully ponder, "How Lucky Can We Get!" – while pointing with pride to our small, dedicated Working Board, further enhanced by Lisa Bosler's supernatural talents as Program Administrator.

Rolling right along on these newly well-oiled wheels, we face the Here and Now – and our Future – with energy, confidence and dedication to the community we serve which in turn provides moral support and sustainability as our "life-line!!"

For both those who have personally experienced this year's Members' Reception's phenomenal exploration of the demanding World of the Hands-On Family Home Health Caregiver – and those who may be wishing they had -- we are breaking with tradition by supplementing the newsletter's Front Page formal account of the evening's events. In so doing, we are further responding to and building on the intensity of the excitement, interest and response generated by Carol Levine's presentation. Clearly, reacting to the palpable pain of the audience's collective seared nerves, we are

confidently venturing forth into the World of Hands-On "Home Health Care." For the Family, a new era fraught with grief, uncertainty, shock, denial – dependent on physical and emotional strengths, often offset by illusions, glimmers of wishful thinking, dashed by false hopes and unrealistic expectations; while still further compromised by back-breaking "Juggling Acts," created by the drain on financial resources from the demanding dual role of "Caregiver cum Breadwinner!" And yet, while seemingly stressed to the limit, never questioning the need for being there, for both the



*Former NYCCHCD Board Secretary  
Mary L. Meyer with husband Karl Garlid.*

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pain and comfort of caring for a loved one, with the ultimate blessing of anticipated peace for both! Never giving up hope, while not daring to deny the inevitable! And yet, overcome by disbelief, grief and stress, compelled to ask oneself, “What Should I Be Wishing For?”—still not quite ready to deal with the answer!

Critical conflicting issues abound! No denying them! But for most, “Going Forward” is the only acceptable directional signpost reading, “Green Light!” “Go! Good Luck! Take It Easy! Peace Be With You!” Added to these super-pressing, attention-demanding issues is the impact of the stark reality of the rapidly-growing, culturally-diversified aging populations, perhaps somewhat inspired, yet surely bewildered and even more often troubled by Science and Medicine’s latest prophecy of “Old Age” at just “90!” Forget About It! We’re on to Living to 100! And Beyond! ... – yielding a tentatively positive response, yet a strong, unmistakably negative, “Thank You, But No Thank You!” – “Spare us this significantly confusing, so-called tantalizing Bonus.”



*NYCCHCD Board Member  
Dr. Judith Lauterstein*

The overwhelming volume of National Health Care / Medical plans for the future reveal a barrage of worrisome questions – going beyond government provisions – reaching into the realm of personal and family responsibilities for home health care! “Who will support me – Be there daily, weekly, 7 days / 24 hours, around the clock? – How strong are the shoulders bent on and by this potentially debilitating and stressful load – financially, physically, emotionally – and at what ultimate overall cost? And further still – having created a growing dependency on their services, who will be closely monitoring home health care rendered by both the “officially regulated” agencies, who, by virtue of their licensure and proven quality performance, are starkly contrasted by an even more pressing need to monitor the self-designated “ad hoc” “word-of-mouth” unofficial, unregulated resources cropping up to fill this ever-demanding, ever-growing need?” A \$64 question clamoring to be answered!!



*Beatrice W. Greenbaum,  
seated, with Shirley Solomon*

NYCCHCD’s reputation for “Parsing The Issues” with stark reality and in good faith – Here Again Comes Front and Center! By adhering to our traditional response to our most recent Members’ Reception, our Program Agenda for the upcoming year will reflect the issues raised by both the designated Speaker and responsive audience!

Taking this one step further, albeit a giant one, we will appropriately continue to share programs with similarly concerned organizations. To wit, sharing with the New York Foundation for Senior Citizens – NYC Long-Term Care Ombudsman Program, led by Shirley Solomon, Assistant Program Director, the issues of both Co-Morbidity and the Ombudsman’s Role in overseeing the patient’s care in long-term health care facilities.

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In 2005-2006, under a grant from the Fan Fox & Leslie R. Samuels Foundation, NYCCHCD trained a group of deaf people to become cognizant of and proficient in dealing with the legal, official healthcare documents (i.e., NYS Health Care Proxy and Living Will) so they could educate the deaf community on the accessibility of these documents. Building on our ongoing role servicing the deaf community, we have been named Co-Sponsor for a special pilot training program—funded by The Sunshine Lady Foundation and led by NYCCHCD Board Member Dr. Judith Lauterstein—for creating a core of “signing” and/or deaf home health aides in the metropolitan New York area who will be sensitive to the unique linguistic and cultural needs of the deaf community.

In addition to these major concerns, we are actively participating in responding to the need to address the role of Patient ← → Person, as reflected by Christopher Lukas’ poignant letter on his personal experiences featured in this newsletter.

The new projected problems, as an outgrowth of the home health aide situation, as expressed in this newsletter, are but a glaring example of one of the major issues we are prepared to address. This has never been as apparent as now as we confront the demanding, oncoming changes in the proposed health care system.

Mindful of the weakened economy and the ongoing needs affecting all small organizations of similar intent and vigor, we turn to you, Our Constituents, for your ongoing support to help us sustain the viability of Our Mantra: “We need you – you need us – and the community needs us both!”

Thank you,



Beatrice W. Greenbaum  
Executive Director and Chairperson



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## PATIENT ← → PERSON

By Christopher Lukas

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Dear NYCCHCD:

When you get cancer, you start thinking death. And when you start thinking death, you start asking, “How do I want to die?”

Or, at least, I do.

I am now 74 years old, and I’ve survived 17 years of recurring non-Hodgkin’s Lymphoma (with radiation and chemotherapy), prostate cancer treatment, and a surprise lymphoma cropping up in my arm. I’ve also just finished a year of mourning after the sudden death of my wife. I think about death a lot.

Some years ago, when I was making videos for the Citizens’ Committee, I went to a hospice in the suburbs of Baltimore. In a room, painted in gentle shades of beige and purple, a woman lay in bed on an oxygen feed. Sitting near her were her son and husband. They chatted amiably, and only when I was told by a nurse that the woman was near death, did I sense anything near despair in any of them. When an aide asked the woman if she had any pain, she answered that she did not, and I realized that the concept of comfort care really does work.

Comfort was what these nurses and aides were all about. Comfort for the patient; comfort for the family members. Learning to say “good-bye” is difficult under any circumstances, but the hospice workers know how to help both patient and loved ones do it. “Say Good-bye,” one doctor said. “Say *Good-bye*, and *I forgive you*, and *Do you forgive me?*”

Hospice can help you live through your last months, or even years, with equanimity. It can be administered in your home, where one man I saw was being seen by hospice personnel during his fight with Lou Gehrig’s disease. His wife was grateful that the hospice team visited daily to make sure she wasn’t overburdened; that he had the nutrition he needed; that he wasn’t in pain.

“Hospice Team.” Makes it sound like Roto-rooter or the exterminator. Quite the opposite. These people are there to take care of people in the deepest sense of the word. The wife of the man with ALS said she couldn’t have been the good caregiver she was at home without the hospice people. “Not a chance,” she said. “They give me the time to breathe!”

While I was having chemo, I spent months at home, jittery on steroids, devoid of energy, full of anger and self-pity. No visiting nurse, no hospice care (hey, I wasn’t *dying*), no kind words from nurses or doctors. But I had my wife. She was not only a friend and a fireball of energy and efficiency, she was a brilliant psychotherapist. But I miss her for another, more poignant reason.

She didn’t offer me aspirin and chemo; she didn’t change my bedpan or put cold compresses on my brow. But she was my caregiver in many other ways. She kept me exercising. She kept me going out to movies and theatre. She encouraged me to write, to keep *living*, to keep breathing.

I saw the pain in her eyes when I faltered. She told me that she actually felt pain in her heart when I was ill. I valued her empathy in the same way her patients must have valued it. She gave me her time and her heart and her care. When I had a fever, *she* drove me to the emergency ward and badgered the doctors to see me “Right Away, Now!” When I missed Thanksgiving (I had pneumonia), she brought turkey to my hospital bed. She made me see that caregiving is a full-time occupation, even when you already *have* a full-time occupation.

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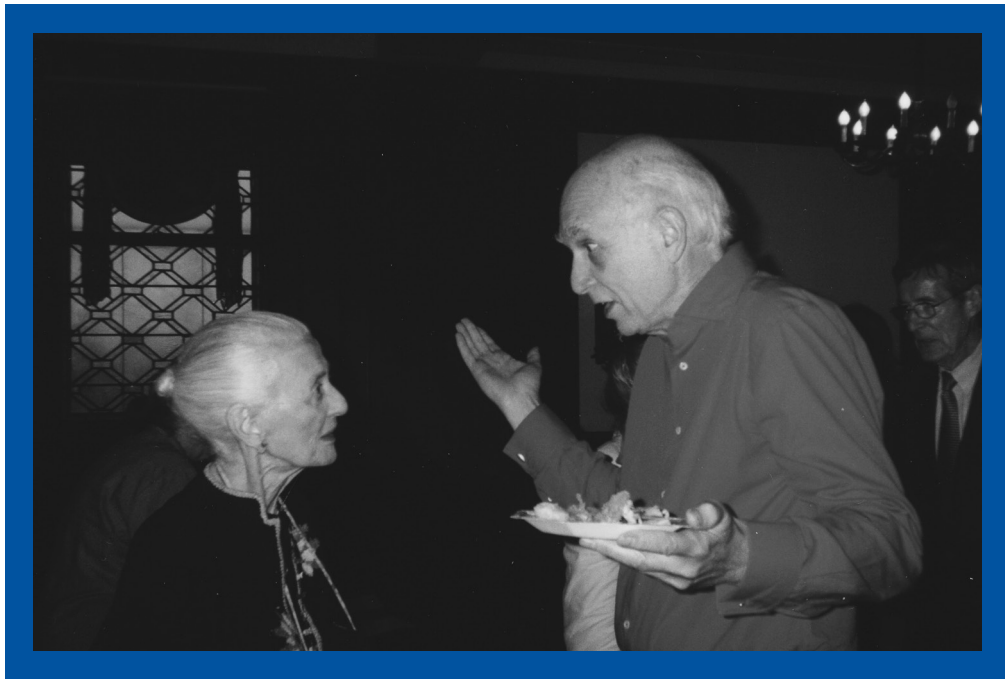
In June of 2007, she retired from her job. Ostensibly, it was a decision based on her wish to paint full-time. But I think it was because she sensed that my cancer might return. She wanted to be available.

Instead, in April of 2008, she died of cardiac arrest.

Despite the burden of caregiving, despite knowing how *my* heart would have pained me to see my wife in pain – I wish I could have returned her caregiving favors. I would have put up with the exhaustion, the irritability, the need to be free of obligations just to give back to her what she gave to me.

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Christopher Lukas is the author of [BLUE GENES: A Memoir of Loss and Survival](#).



*Beatrice W. Greenbaum and Christopher Lukas conversing at an NYCCHCD gathering.*

# ONE LOSS MAY HIDE ANOTHER

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By Carol Levine

At a railroad crossing at the edge of a Masai village in the heart of Kenya, the late poet Kenneth Koch saw a puzzling sign: “One train may hide another.” It turned out to be a warning: Before you cross the tracks, make sure the first train did not block your view of another train coming straight at you.

The sign led Koch to ponder its deeper meaning. In his poem, “One Train May Hide Another,” he describes the many ways in which one event, one emotion, one experience, may hide another, even more profound meaning.

I thought of this poem recently after my mother died. This was a sad though not tragic event in my life. But in opening my heart to grief, I found that I was really mourning the loss of my husband’s companionship, support, and love. I have lost my life partner, and not to death, which is final, but to a continuous series of reminders of what was and what might have been.

It is by any measure a terrible story, and the telling does not get easier with time. In January 1990, we were both in a terrible automobile accident on an icy road about one hundred miles north of New York City. My husband was driving; we were both wearing seatbelts. The car skidded, hit a guardrail, and flipped over and slid down an embankment.

Amazingly, I was unhurt. My husband suffered a severe traumatic brain injury. A testament to one of American medicine’s major successes, saving the lives of trauma patients, he survived, but with permanent severe disabilities. For the four long months he was in a coma, I read to him, played his favorite music, and showed him family pictures. When he gradually emerged from the coma, his thinking was chaotic. He had to relearn basic words and concepts. His moods alternated between rage and suicidal withdrawal.

In the anxious weeks he was in intensive care, I was still a wife. Doctors and nurses informed me of each day’s progress or setback and treated me with kindness and concern. When he was no longer in immediate danger of dying, however, I became invisible, only to become visible again when I was expected to be the manager and hands-on provider of his total care. In retrospect, I date my rite of passage to the first day of my husband’s stay in a rehabilitation facility. A nurse stuck my husband’s soiled sweat pants under my nose and said, “Take these away. Laundry is your job.” Without knowing it, or understanding the consequences, I had become a family caregiver, a role I continue to play to the best of my ability while longing desperately to be just a wife.

My husband’s rehabilitation and my anguish were worsened after a medical error caused the eventual amputation of his right forearm. When my husband came out of the coma, he repeatedly asked me to put his wheelchair in front of a mirror. He believed that his lost arm had been placed somewhere else on his body and that I was not showing him where it was. The psychologist at the rehab facility was kind, but the physical therapists wrote off any possibility of his using a prosthesis or learning to use his left hand. My calls to the doctors who had promised me he would have a full recovery went unanswered. I was on my own, and I felt, and continue to feel, abandoned by the very system that saved his life.

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Today, fourteen and a half years later, my husband is essentially quadriplegic, has significant cognitive deficits, and is totally dependent for all his basic needs. Eventually, I brought him home from rehab to a new and more accessible apartment and began the daily regimen of managing his care and supervising the home care aides who were essential to move, bathe, dress, and feed him.

Providing him with the best quality of life possible under the circumstances requires an enormous managerial effort, the assistance of strong and patient home care aides, and a lot of money. While the medical side of the health care system sees me as a family caregiver, the financial side sees me as a wife and therefore the bill payer. As a spouse, I am legally responsible for the cost of his care; my only option for financial assistance was to “spend down” all our assets, become impoverished, and thereby become eligible for Medicaid. (This requirement does not apply to adult children.) I chose to keep working, not just for the income, but as the only way I could see to retain my own identity.

Compared to my husband’s constant and overwhelming needs, my mother’s seemed manageable. She had reached her ninetieth birthday, and until a year earlier she had been in excellent health. Even after surgery for colon cancer, she had been able to maintain an amazing level of activity, outliving by many months the most optimistic prognosis. She lived in a small town in upstate New York, quite difficult to reach from New York City, where I live, and even harder to reach from Montana, where my sister lives. Even so, we kept in constant contact with her, visiting whenever we could and making sure that she had everything she needed. With a team of excellent home care aides and hospice services, she was able to stay at home, where she firmly wanted to be and where she could be in charge as she always had been.

The last few weeks were hard, as she lost strength and coherence. Alerted by the hospice nurse that the end was near, I flew to be with her. She died peacefully, as I held her hand and whispered the “Sh’ma,” the prayer that Jews are supposed to say as their last words. She used to tell me how her father, whom she adored, had taught her to say this prayer every night before she went to sleep.

The small Jewish cemetery, which I remembered from my father’s death twelve years earlier as a bleak and wintry place, was lush and green in summer. Their graves are next to each other on a gentle rise, next to those of two of their closest friends. It seemed like the cemetery set from the last act of Thornton Wilder’s play *Our Town*, where the dead residents of Grovers Corners speak of their past and welcome new arrivals. I could imagine the two couples, my parents and their friends, chatting through eternity about their children, their businesses, and the goings-on in town. At the end of the service, a bright yellow finch suddenly flew low over my mother’s open grave and disappeared into the sky.

All in all, a “good” death, as deaths go. Certainly, I felt a sense of loss and, after so many months of anxiety, the finality of her passing. The rabbi who conducted the service said to my sister and me, “Now you are orphans, and you must let people take care of you.”

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Perhaps it was those words, or perhaps it would have happened anyway, but in those first few days after the funeral I began to feel intense grief and anguish sweeping over me. Just as one train can hide another, one loss can hide another loss, and if you are not careful, you can get hurt. The hurts I had buried over my husband's condition were reopened, with a ferocity that surprised and even frightened me.

From the outside this fragile house of cards looks solid. I have, everyone assumes, reached some sort of "closure." I have "moved on with my life." After all, I work full-time, directing the United Hospital Fund's project on family caregiving, which is making a difference in public and professional awareness about the realities of taking care of an ill person in our complex health care system. My professional life, which started late because I stayed at home while my three children were young, is flourishing. I travel to give talks and attend meetings.

But beneath my calm, in-control exterior is a void that can never be filled. There is no closure, if there ever can be for anyone in this situation. My husband's occasional flashes of wit and cogency, rarer with each passing year, stab me with sadness even as I laugh and compliment him.

When I told my husband that my mother was dying and that I would be going upstate to be with her, his only response, one I totally understood, was, "When will you be back?" His world has become so constrained that he cannot think beyond his immediate and urgent needs. I, who always looked to him to take charge, am now the captain, purchasing agent, navigator, and part-time crew for our plucky but overloaded little ship.

Had our dreadful accident not occurred, he would have, should have, been with me on this last journey to my mother's bedside. He would have comforted me, taken care of some of the arrangements, made sure I slept and ate, and maybe helped me laugh a little. My mother loved my husband; and he was always kind and gracious to her, even more accepting of her whims and idiosyncrasies than I was.

This renewed awareness of what for me is the real tragedy of my life became even more acute as my sister and I, and two of our daughters, began the difficult job of deciding what to do with my mother's belongings. As we went through drawers and closets, we kept uncovering mementos from my marriage. For several years my husband had worked for an airline, giving us an opportunity to travel that neither of us had had before. Wherever we went, we sent little gifts—a bunch of amethyst-colored glass grapes from Brazil, a porcelain figurine from Denmark, a coral necklace from Hawaii. My mother had carefully preserved each gift, either placed just so in its specially chosen position in her living room or neatly wrapped and marked in her dresser. And each gift reminded me acutely of that happier time when my marriage was a real partnership.

Even more painful were the postcards she had saved, most of them written by my husband. I had forgotten what a good writer he was, able to describe the essence of a place or an experience in the tiny space of a postcard. There were letters as well, telling my parents how much he loved me. One particularly poignant one, which I had never seen, was written

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to my mother after my father's death. In it he told her how well she had managed this difficult time, how strong she was, and how much confidence he had that she would be able to find a new life for herself.

How much I missed him! I had grown so inured to simply getting through each day, each crisis, each challenge, that I had let the part of me that still grieved lie dormant. And yet it took nothing at all—a postcard, a letter, a trivial object—to bring it all back.

Did I feel guilty about mourning my husband, who is after all still alive, when it was my mother who had died? Yes, a little, although I was comforted by knowing that I had done everything possible to make her last year full of love and caring. I was so grateful to her for keeping all the things we had sent her, especially since in the various moves I have had to make since the accident I have thrown out many other such reminders. I think she would have understood that grieving for my husband did not mean I cared less about her death. It only means that I had learned that one loss may hide another.

Now, after her death, I have slipped back into my earlier mode of accepting the unacceptable. My mother's belongings are distributed among my sister and me, our children and grandchildren, and her friends. My husband's condition remains the same. I go on.

In rereading Koch's poem, I find that certain lines have new meaning:

When you come to something, stop to let it pass  
So you can see what else is there. At home, no matter where,  
Internal tracks pose dangers, too; one memory  
Certainly hides another, that being what memory is all about.<sup>1</sup>

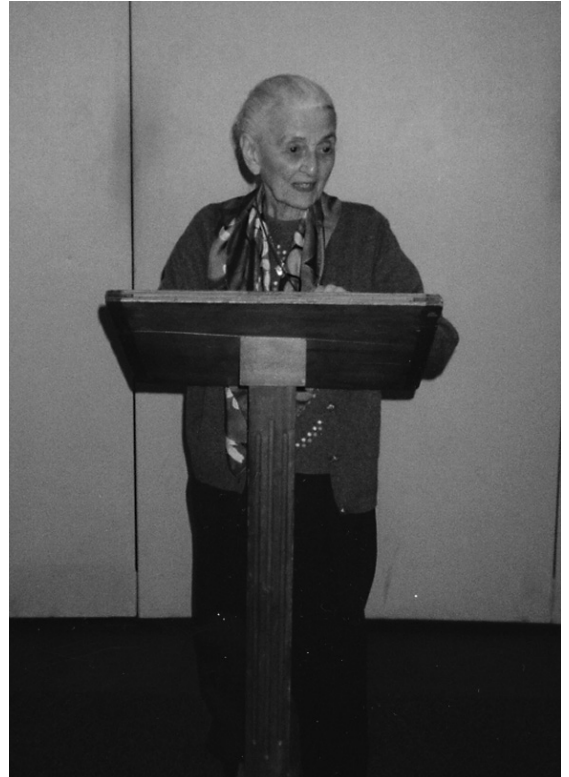
1. Kenneth Koch, "One Train May Hide Another," in *The Best of the Best: American Poetry 1988-1997*, ed. Harold Bloom (New York: Scribner, 1998), 171-173. First appeared in *The New York Review of Books*, April 8, 1993.

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Carol Levine, "One Loss May Hide Another," *Hastings Center Report* 34, no. 6 (2004): 17-19.



*Beatrice W. Greenbaum with NYCCHCD member Dr. Nathan Ionascu*



*Beatrice W. Greenbaum - Chairperson and Executive Director, NYCCHCD*

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**UPCOMING EVENTS:  
LOOK WHAT'S COMING UP!**

**INTERACTIVE "LET'S TALK" DISCUSSIONS**

***You Talk - We Listen***

***We Talk - You Listen***

(Date / Time / Place TBD)

***You, Your Family, Your Doctor  
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