

# The Greening...

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Human Agenda In Health Care” featuring Anna Quindlen’s public and personal views of medical care experiences.

Our semi-annual Let’s Talk discussion series never fails to meet expectations of our members at over-subscribed workshops on provocative topics — “Proxy at the Bedside”, “Hospice at the Crossroads”, “Caring for the Elderly”, “Who’s Caring for the Caretakers?” and “Am I My Parents’ Keeper?” Our annual Members Reception attracts marquee speakers and SRO attendance.

Never able to refuse a request for a speaker, our Community Outreach programs have taken us into high schools, senior citizen’s centers, hospitals, nursing homes, houses of worship.

Not surprisingly, our organization has taken on a life of its own. Our membership has shown significant yearly growth both in numbers, interest and support. Networking with local similarly-purposed groups has broadened our constituency, and enhanced our visibility and reputation. Linkages with compatible statewide organizations with a view to expansion is now a top priority. Our goal to provide all New Yorkers with opportunities for empowerment has begun to be realized on Long Island, and in Westchester and Rockland Counties.

As a typical not-for-profit entity, the NYCCHCD relies on membership dues, program registration fees, and project-driven funding. We have been particularly fortunate in capturing the attention of several family foundations for unrestricted operational grants. Our greatest and latest pride of accomplishment is in the funding grant from the Open Society Institute, Project on Death in America, for our two-year project, “Senior Partners In Health: Learning to Use the Physician-Patient Relationship as a Prudent Patient.” Further proposals for project funding are being developed for Managed Care Focus Groups, and for a “Day of Ethics” program on big-ethical issues in the high schools.

Time and again we’ve been asked, how can your small band of miracle workers be so timely, so on-target with all you do? What gives you such keen sensitivity to individuals and communities?

Here again, the answers are straightforward.

- We never stray from our mission
- We take a neutral, impartial stance
- We focus on people
- We face their challenges from their viewpoints and in real terms

- We strive for equity in addressing relatively intangible values and concrete purpose
- We are firm in our belief that only an Informed Citizenry can be an effectively Involved Citizenry
- We entrust education, collective deliberation, communication with the keys to Citizen Empowerment

In all of the above and more, as we reflect on the grassroots approach, we are always mindful that, while there are no perfect solutions — just preferable

ones — they must give voice to all clusters in our society.

*Beatrice Greenbaum, HA’82, is Chairperson and Executive Director of the NYCCHCD. She is also an active participant in, and a board member of, numerous committees and organizations committed to the delivery of quality health care. She is the recipient of several awards including the “Liberty Bell Award” and the 1997 Health Advocacy Award for her outstanding service to the community in the field of health advocacy.*

## Polly Rothstein: Clout & Credibility

by Deborah Hornstra, M.A.

**P**olly Rothstein’s desk is, as usual, overflowing with papers, but she finds everything she needs easily. The walls of her White Plains, New York, office are covered from floor to ceiling, one with color photographs of birds she has sighted, the others with clippings and memorabilia from Rothstein’s long career as an advocate for the right to abortion. As founding president of the Westchester Coalition for Legal Abortion, an organization that dates back to Roe v. Wade, Rothstein is probably the single most important reason why Westchester is and always has been steadfastly pro-choice, despite the county’s otherwise deserved reputation for conservatism.

*“It’s a numbers game,  
and numbers make power.”*

The consummate grass-roots organizer, Rothstein has made it her personal crusade for 25 years to use the ballot box to ensure abortion remains a legal medical procedure in New York State. The Coalition’s database comprises 70,000 households, or a full third of the county’s electorate. The list was compiled using what Rothstein calls “massive systematic telephone canvassing of all registered women voters whose phone numbers we could get.” (The first thing she did when this reporter entered the room was add

my name and unlisted phone number to her files!)

Why is Rothstein so focused on the list? “It’s a numbers game, and numbers make power,” she says adamantly. In the years immediately following Roe v. Wade, the Coalition kept its names on paper, but in 1980, Rothstein computerized the process (originally using a mainframe), which made it easier to manage and expand the list. With increased numbers, says Rothstein, “Our credibility soared. It was clear that clout matters.”

“The key to keeping abortion legal,” declares Rothstein without hesitation, “is electing the correct people.” In the November 1997 race for County Executive, Westchester voters were courted by two candidates who both claimed to be pro-choice. The Coalition, however, declined to endorse local mayor Ted Dunn, who had spoken out against “partial birth abortion” and in favor of more restrictions on the procedure. (Rothstein later said Dunn threatened her with retribution for withholding her endorsement.)

Instead, the Coalition backed only longtime county clerk Andy Spano, whose prochoice record was not in dispute. Coalition staff and volunteers made over 50,000 phone calls from their seventeen phone lines in the weeks prior to the election, and Spano roundly defeated Dunn. It’s just the latest example of the political influence Rothstein and her Coalition wield in Westchester. Every election, the county is blanketed with the Coalition’s bright yellow “Pro Choice Voting Guides.” The guides spell out each candidate’s position on abortion, which Rothstein calls a “gut issue, a bottom-line issue.” The lat-

est guide ends with the stern admonition: "Don't even THINK of not voting!"

"I would never recommend not voting in an election," says Rothstein, a firm believer in participatory democracy. What to do when faced with only unacceptable choices? "I would suggest writing in a name that makes your opinion clear." (Rothstein herself has received numerous write-in votes for county offices.)

Rothstein makes no bones about the political nature of her advocacy efforts. Donations to the Coalition are not tax deductible, and that's fine with her. "Our purpose is political, not educational. We are here to lobby and elect people." And elect people they do, partly because, as Rothstein notes, "women are willing to cross party lines in high percentages to support pro-choice candidates."

In a place where 70.5% of Republicans (as well as 61.3% of Conservatives, 77.6% of Independents and 82.5% of Democrats) identify themselves as pro-choice, one might think the Coalition's work is done, but Polly Rothstein doesn't think so. She is concerned with the growing push for "fetal rights." ("The woman is the patient, not the fetus," says Rothstein.) She worries about the stigma that attaches to doctors who perform abortions.

Right now, Rothstein is fighting New York State Assembly Bill 5987, the so-called partial birth abortion ban, which Rothstein calls a "false issue that would prohibit 85% of all second-trimester abortions." Rothstein has even drafted a parody of the bill that calls for the permanent removal from consideration of "any legislation using nonstandard terminology, such as 'partial birth abortion,' not found in medical literature or used in medical practice."

Rothstein also looks beyond abortion rights to other issues. "There are so many problems with our health care system, so many needs going unmet." Chronic illness, such as the Alzheimer's Disease that afflicts Rothstein's husband, is "an overlooked area with huge gaps where advocacy is needed." But in the end, this powerful advocate with the electoral emphasis will forever be associated with abortion rights, which, as she gently reminds us, "affect 51% of the population."

*Deborah Hornstra, HA '97, writes on health topics and was recently appointed Communications Officer at the Center for Health Care Strategies, Inc., at Princeton University.*

# "A Remarkable Thing Happened in Chambersburg, PA"

by Phyllis Ann Bailey, M.S.W.

This is a story about the development of a post polio support group in a small South Central Pennsylvania town nestled in the Cumberland Valley thirty miles west of Gettysburg. This group has become well-educated consumers and thus "empowered" to educate their personal physicians and become partners in their medical care. The group was recently recognized as a health advocacy model at the annual national conference sponsored by the University of Alabama and the Alliance for Continuing Medical Education which was held in San Diego, California.

*...our physicians were too young to have seen a case of active polio, let alone be able to recognize PPS.*

Before I go any further, it should be noted that I am a polio survivor, having had polio at age seven and been given the whole gamut of treatment including iron lung, years of physical therapy, bracing and orthopedic surgeries. According to the U. S. National Health Statistics, there are over 650,000 survivors of paralytic polio in the United States alone. Over half of these have been experiencing new difficulties that are related to their "old polio." These new health problems include joint and muscle pain, muscle weakness, fatigue, sleep, breathing and swallowing disturbances, and an increased sensitivity to cold. The most widely accepted explanation is that nerve cells damaged by the polio virus decades earlier, and the neighboring nerve cells that took over for those killed by the virus, are now wearing out. A national grass roots movement emerged during the mid-1980's to help address the new problems facing polio survivors.

During the early 1980's, I had discovered a post polio support group in Bethesda, Maryland, where I was then working and living. It was there that I learned of post polio sequelae (PPS), although I was at that time not experiencing any symptoms. In 1990, I retired and moved with my husband and dog an hour and a half away to Chambersburg, Pennsylvania. Shortly thereafter, I began experiencing some of these symptoms myself and looked for a support group so as to have a resource for future treatment. There was not a support group to be found. The closest one was a two-hour drive away. During my search, I was in touch with our local Easter Seal Chapter and in March of 1994 its president asked me to participate in a local Easter Seal Telethon, since there was such a lack of awareness of PPS on the part of the general public. Following the telethon I was again approached by the President of our local Easter Seal Chapter to test the community to determine if there was sufficient interest in forming a post polio support group.

After some local publicity we held our first meeting in May of 1994. The response far exceeded our expectations. There were thirty attendees, making it necessary for us to move from the conference room at the Easter Seal facility to the entrance hallway. At that time we started with seventy-five names on our mailing list. The response included people from four Pennsylvania counties, and nearby areas of Maryland, Virginia and West Virginia. The following meeting in June had over fifty people in attendance. Since some of these people were in wheelchairs, scooters, some using walkers or crutches, it was quickly evident that the physical space provided by Easter Seal would not be sufficient. At that second meeting we had also invited a representative from our local Chambersburg Hospital Education Department who, when she observed our cramped quarters, volunteered to find a more suitable meeting place in the hospital lecture facility. As this was a recent addition to the hospital it was also "handicapped accessible", and we have been using that facility ever since. This hospital representative now serves as