

HEALTH ADVOCACY BULLETIN

The Journal of the Health Advocacy Program at Sarah Lawrence College

VOLUME 6, NUMBER 1

SPRING 1998

Rediscovery of the Grassroots: Radical or Reactionary Trend?

by Terry Mizrahi, Ph.D.

Politicians, professionals and patients seem to have all re-discovered the virtues of so-called "self-help" and grassroots activities or what in the 1970's Alan Gartner and Frank Riessman identified as the "a-professional dimension of helping" and Harry Boyte labeled the "backyard revolution." This active formation of consumer and community groups has had multiple purposes over the years: providing support, raising consciousness, increasing resources, and changing policies; or in the language from Health Advocacy Course I, promoting "case/individual and cause/class advocacy." To this end, I applaud the many wonderful examples of groups described in this issue, many initiated by alumna of the Sarah Lawrence Health Advocacy Program and their colleagues. These are illustrations of innovative programs advanced by committed and competent professionals.

However, I would like to raise a few caveats, and caution leaders and participants as they advocate for and plan such activities. We are in an era of political and economic conservatism. This has led to a retreat in the government role in meeting human needs, a retrenchment of government-funded benefits and services, a take over of health and human services by the private, corporate sector, and even a redefinition and reframing of health care needs and services so that the public ultimately expects and demands less from their employer, their community and the state. It is also an era of downsizing and deprofessionalization while many public officials advocate for personal responsibility.

It is no wonder that the virtues of programs that call for self-help and that turn treatment over to consumer and family members are being extolled. However, these seemingly cheaper alternatives to professional care present several problems in the context of the conditions I described above. First, while more responsibility is being

given to and expected by "natural helpers and supports", there are not the concomitant rights, redress and resources being provided to them. These methods must be based on appropriateness, accountability and effectiveness. For that to happen, resources and expertise must be provided. Without these, a "blame the victim" outcome could emerge as risk and responsibility is shifted to the patients and their helpers. While the Sarah Lawrence Health Advocacy Program philosophy has been a strong proponent of organized consumer/community involvement and influence, we have done so based on a social and ultimately, legal philosophy that promotes a "right to health care." This does not exist now.

Second, by accepting the term "self-help", people play into the hands of those who glorify individualism and competition. The term is a misnomer; it needs to be redefined as "mutual aid and support". The philosophy of the 12-step and related grassroots efforts recognizes that people can't and don't have to do "it" alone; indeed, that movement provides a community of belonging and acceptance, a group of people who can empathize with and support each other because they have all been there. Such groups foster interdependence and recognize the common experiences that bind people. It is the common and group definition of social problems that make these grassroots efforts so powerful. However, these programs are neither quick, nor easy, nor the only "fixes" for people. Hopefully, we will all continue to advocate for adequate regulation and resources to meet the needs of people, while we engage them in working on their own collective solutions to problems.

Terry Mizrahi, Ph.D., is a professor at the Hunter College School of Social Work in New York City, and is the author of numerous books and articles on community organizing and related fields. She was hired to join the faculty of the Health Advocacy Program shortly after it started as a result of the students organizing to obtain more content in "advocacy" in a curriculum they were experiencing as focussing too much on "health."

In This Issue

Rediscovery of the Grassroots: Radical or Reactionary Trend?	1
The Greening of a Health Advocacy Organization	3
Polly Rothstein: Clout and Credibility.	5
"A Remarkable Thing Happened in Chambersburg, PA".	6
Amputee Support Groups: Patient Advocacy In Action	8
Thriving in a Small Community: The Ithaca Breast Cancer Alliance	9
Grass Roots = Cutting Edge	11
Self-Empowerment: The Independent Living Movement	12
Family Caregivers Take Charge	13
Rally for America's Health	14
Joan Marks to Retire	15
Congratulations, 1998 Graduates.	15

Plus

From the Editors	2
Advocacy Online.	2

From the Editors:

Reading the material for this “grassroots” issue, we are awed by the commitment and caring that these articles demonstrate. They are an indication of the tremendous need we have not only for information and insight, but for community. They also reflect enormous energy, hard work and a solid record of achievement that deserve profound appreciation. We are extremely grateful to each of our contributors. Some are Sarah Lawrence Health Advocacy graduates. Some are health professionals, some are patients who of necessity have become advocates. There is often no clear demarcation between “patients” and “professionals,” but a very clear awareness that when everyone works together, amazing things can happen. We salute you all.

We are saddened to hear of Joan Marks’ departure from Sarah Lawrence College. It is hard to imagine the Health Advocacy Program without her. Dean of the College, Barbara Kaplan, put it so well: “Joan’s leadership in the development of this Masters program, which was the first of its kind, has been characterized by an acute sense of the changing health field and an imaginative engagement with health issues”. We thank her for having helped put together such a worthwhile curriculum and wish her all the best in her retirement.

— Karen Martinac and Irene Selver

Special Note

As Deborah Hornstra starts her new position as Communications Officer at the Center for Health Care Strategies Inc., affiliated with the Woodrow Wilson School of Public and International Affairs at Princeton University, we take this time to wish her all the best and to thank her for all she has done for the Health Advocacy Program and for this publication. See the Health Advocacy Program website she has created and which includes the *Bulletin*: <http://www.slc.edu/pages/h/health>.

The *Health Advocacy Bulletin* is published twice a year by the Health Advocacy Program at Sarah Lawrence College, One Mead Way, Bronxville, New York 10708.

Editors: Karen Martinac
Irene Selver

Faculty Associate: Marsha Hurst

Production: Donna Scott

Program Director: Joan Marks

Phone: Karen Martinac at (253) 761-3070
Irene Selver at (212) 222-2576

E-mail: healthad@mail.slc.edu

All material in the *Health Advocacy Bulletin* is the property of the authors and may not be reprinted without permission. Opinions expressed are not necessarily those of the editors nor of the Health Advocacy Program.

ADVOCACY • ONLINE •

Even a brief session of “web browsing” yields a stunning number of sites providing information and support on health and illness. Ten years ago, a mere patient or lay person needed special permission (if this could be obtained at all) to use a hospital medical library. Now an almost overwhelming amount of information is there for the taking. As seen in some of the pieces in this issue, the Internet is revolutionizing the doctor-patient relationship, and giving new meaning to the concept of “informed.” Here are a few sites germane to the topics discussed in this issue — and an extra or two.

American Health Decisions — www.ahd.org/ahd.html

Amputee Coalition of America — A new web site is under development at amputee-coalition.org/draftsite. A joint announcement with The Centers for Disease Control and Prevention on the creation of the National Limb Loss Information Center and its goals can be found at www.oandp.com/organiza/aca/limbloss.htm

Centers for Independent Living — Many local centers have web sites. The “original” in Berkeley, California, is at www.ciberkeley.org/

HIV/AIDS — Many, many sites exist both nationally and internationally. The American Foundation for AIDS Research provides a long list of links to information and support at www.softdisc.com/customer/lucareli/hivlinks.html

Head Injury Hotline — www.headinjury.com/brain A very interesting, patient-advocacy-centered site providing “information and referrals, tools and maps.”

National Family Caregivers Association — www.ntcaca.org/

Post Polio — Polio Remember Your Strength Foundation provides extensive listings of educational and support services at www.prys.net/

Westchester Coalition for Legal Abortion — www.wcla.org

Sarah Lawrence Health Advocacy — www.slc.edu/pages/h/health

The Greening of a Health Advocacy Organization

by Beatrice Greenbaum, M.A., M.P.A.

When invited to write an article on grass-roots advocacy organizations and how a community conceives, delivers, and nurtures a healthy one, my first response “why not?” was my typical approach to any new venture or request. Three areas need to be explored: what are grass-roots organizations; why do they exist; and how are they built?

The very words grass roots when applied to community organizations trigger a stream of stereotypical images, replays of the plots of old-time favorite movies. Challenged by pressing issues of local importance often polarizing and one-sided, a self-starting unit of like-minded citizens roused to action by a hero-type leader meets to talk, to deliberate, to listen to their neighbors’ voices, to seek solutions and reach consensus. Now fill in the picture with a Village Green, Town Hall, Community Center, and a picket fence or two — and there you have it: the perfect grass-roots setting in which to “think locally, act locally” in true democratic spirit.

However, given the areas and population densities of an urban center, how would city folk fare? Would they not be disenfranchised and lose all opportunities to have their ideas and beliefs help shape the public policies that affect them?

If changes come from an engaged citizenry, if public conversations foster self-reliance and overcome differences and diversities, how ought we not find a crack in the urban cement for even a few blades of grass to peak through?

At no time would the loss of an option to advance deliberative democracy be felt more keenly than in our present drastically changed and rapidly changing, disoriented health-care environment. At no time would the need for action be more imperative. In the recent past, health care issues confronting individuals and society have entered the scene with the intensity of boom-town growth in both numbers and complexity.

The surge of technological and scientific advances, matched by moral quandaries and ethical dilemmas, has challenged the health care system to strike a balance between conflicting medical needs and their spiraling costs.

And as Jane and John Q. Public are forced to grapple with a broad range of health care choices for themselves and their families, they must also reach beyond their rights to question professional responsibilities and social interests. And they ask questions of themselves and society.

Dare we turn our backs on the millions of American wage-earners who can neither afford health insurance nor qualify for government assistance, and thus remain medically homeless?

...it provides citizens with a common voice, a common purpose...

What do we say to the booming elderly population of friends, family, and neighbors, their lives prolonged by medical miracles, now at the height of their vulnerability, who are in jeopardy of having care sharply limited? Who decides how scarce organs donated for transplantation should be rationed? Who has the wisdom, medical integrity, and the right to weigh the value of one life against another? Have we as individuals and community forgotten to value compassion, justice, and humaneness as integral components of health care.

Palliative care, comfort care, quality of life and death, once in the private domain of the hospice model of care, have gone public. Informed consent, DNR, CPR, the elitist language of the medical profession — all new entries in citizens’ vocabulary of Patients’ Rights, Doctor-Patient Relationships, Advance Care Planning — have tilted the balance of power in end-of-life care.

Clearly, a disquieting atmosphere in which not one sector of our diversified society has escaped having to face these challenges. Professional health-care providers, insurers, policymaking pundits, medical ethicists — each driven by their own special interests — network with their constituencies and establish their own bailiwicks.

But what about our friends Jane and John?

Concerned citizens nationwide, threatened by the swelling tide of polarization, misplaced priorities, and social inequities in the health-care system, sought a venue in which to make their presence felt at the centers of power.

In 1982, Oregon, a health-care trendsetter, organized an extra-ordinary grass-roots initiative to empower citizens to participate effectively at the local and state levels. Nonpartisan, non-profit, dedicated to public involvement, it provided citizens with a common voice, a common purpose for the common good.

In short order, community health-decisions groups across the nation began to demonstrate that when citizens want to understand, debate, and be engaged in personal health-care decisions, they can become stakeholders in public-policy deliberation and development.

By 1988, American Health Decisions (AHD), the Health Care Grass Roots Voice, a national consortium of state citizens’ groups, had been founded by a core of activists from ten states. Acknowledged as the national leader in promoting values-based citizen choices in health-care policy, as a collaborative proactive organization it provides a network of professional resources. By actively enhancing communication and sharing of information and expertise among member states’ groups, it strengthens and nurtures each organization.

Early on, AHD recognized that unless an active, informed public is involved, left to the experts alone, serious health-care problems could not be resolved satisfactorily.

Increasingly, newly formed havens for grass-roots participatory democracy were tapping into diverse groups, bringing people together to clarify individual and community values, to deepen and broaden their perspectives.

From coast to coast, north to south, state health-decisions groups had become catalysts for change, their participating citizens agents for change. Tens of thousands of citizens became involved; community responsibilities were activated.

The Greening of a Health Advocacy Organization

Continued from page 3

In Massachusetts, people gathered in town meetings to discuss the need for universal access to health care. In California, educational programs on the use of Advance Directives reached thousands throughout the state. In Vermont, the issue of health-care resource allocation was debated at community public forums. In Georgia, at focus group meetings, citizens speaking their own minds identified what they value in a health care system. In Oregon, a special health-decision project demonstrated how much citizens truly wanted fair and equitable distribution of health care and resources. The New Jersey Citizens' Committee on Bio-Medical Ethics first saw the light of day in the living room of its founder, Mary Strong, where six similarly concerned enthusiasts were transformed into a statewide organization.

Striking in this overview of stepped-up health care activity momentum was one significant disturbing revelation: New York State was conspicuous by its absence. Given New Jersey's success, it seemed inconceivable — unconscionable — that its next-door neighbor New York had not yet found a way to muster the troops to follow suit. Seizing the moment, in October 1989, a thirty-member steering committee was convened to test the possibilities of going forward. Several meetings later, a smaller group emerged, with motivation and commitment playing the key roles in the decision to go with the consequences on a trial basis.

Homeless, staffless, fundless, but not friendless, this smaller but ever more tenacious group survived. As yet organizationally unstructured, we were generously provided (read blessed) with meeting sites by both the Governor's Task Force on Life and the Law, and a local Unitarian Universalist congregation. By October 1990, now officially named, the New York Citizens' Committee on Health Care Decisions (NYCCHCD) with a Board of Directors and Officers (with myself as the Chair), was ready for action but had no place to hang its hat. Thanks to the National Health Council we had the use of a desk, telephone, mail service, and other such facilities until August 1991, when the Council's move to Washington, D.C. set us on a search for a permanent base. Not even the most fanciful fantasies could have envisioned a site as perfect as our new one at the New York Society for Ethical Culture building.

Legal work done pro bono, incorporated as a membership not-for-profit organization with 501-(c)-3 IRS status, we shifted into high gear to bridge the gap between citizens' health-care needs and values, and those of caregivers and lawmakers.

Our mission statement put a face on our organizational persona: "The primary purpose of the NYCCHCD is to promote exploration of the ethical issues in health care presently facing individuals, institutions, and policy makers; and to provide a mechanism by which these issues can be broadly communicated to the society at large as well as to policy makers at the state level." In short, this can be read "to create a framework for public policy to be fleshed out by an informed public involved in the process, with emphasis on the individual."

...we shifted into high gear to bridge the gap between citizens' health-care needs and values, and those of caregivers and lawmakers.

While many advocacy organizations exist to promote one specific issue, the Citizens' Committee's uniqueness is two-fold. It lies in its non-partisan stance on a panoply of big-ethics issues and in its concentration on the "people" — the citizens who want to listen, to learn, to have their say. This is the road to Citizen Empowerment we have chosen and continue to travel with no distracting detours. In the true grass-roots tradition, we wanted to know what ordinary citizens talk about, and why.

As with any fledgling organization, the Citizens' Committee's mobility remained to be tested and proven. However ambitious our intentions to emulate our more established, expansive, financially endowed state health decisions colleagues, reality reduced long-range strategies to short-term plans. Statewide in intent, citywide in capability, we functioned solely on a

voluntary basis throughout the first year, organizing, setting program goals, providing a series of meetings in the metropolitan area.

Early on, we learned that there are no magic wands to wave to instantaneously provide groups of citizens eager to work to make a difference in health-care policy outcome. Citizens must organize themselves or be organized for meaningful participation, a responsibility to be shared with community leaders at the grass-roots level.

For civic involvement, it is only when the "how," the methods to encourage participation begin to work, that the "what," the program goals, will be achieved. These goals typically common to health decision programs are; to educate the public, to extract information about citizens' values, and to build community responsibility around given issues. To date, our experiences have shown that issue conferences, public forums, local meetings, study groups, and workshops are most successful. We have yet to mount a focus group values survey project.

A rundown of our activities astounds even those of us immersed in planning and implementing on a daily basis. Our major forums assemble health-care providers, attorneys, ethicists, clergy, and concerned citizens to explore hot-button issues. Diversified in scope, and enhanced by collaboration and networking, we bank on creative style as well as content for popular appeal.

To wit: "Physician-assisted Suicide: If it Were Legal Would it Be Workable" played to a full house in 1994 and called for a revisit to the issue in 1996 with "Last Rights: Should the Medical Profession Help Competent People With Terminal Illness End their Lives on their Own?"; "Managed Care: Panacea or Pandora's Box?"; a colloquy exploring the issues raised by the rise of Managed Care; "Way to Go -Everything You Need to Know to Control Care and Decisions near the End of Life"; "Who Supports the Patient? A Collaborative Discussion of the SUPPORT Study." All examples of innovative approaches to critical issues, all audience-producing.

Two inspiring presentations in our Annual David Finley, M.D. Memorial Colloquium were: "Don't Manage Me, I'm No Case," Dr. Robert Butler's account of the changing medical scene; and "The

The Greening...

Continued from page 4

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.

Polly 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

“A Remarkable Thing Happened in Chambersburg, PA”

Continued from page 6

our interface with the hospital when we have special requirements and also arranges space for our monthly meetings. We feel fortunate to have acquired this additional support from our local hospital. Easter Seal has continued to make available its administrative staff to aid us in the printing and distribution of our monthly newsletter.

At these early meetings I heard amazing stories. As members talked and shared their experiences, there were tales of being misunderstood and patronized by their physicians, misdiagnosed and even referred to psychiatric facilities. Some had experienced inappropriate physical therapy and their sensitivity to pain and anesthesia was not even recognized. One member who had polio at age five and wore two long leg braces with a pelvic band had to be hospitalized for a fracture. At some point during her rehabilitation, the physician demanded that she try to stand without her braces. This was rather ridiculous since she had needed the support of these leg braces since childhood.

“How many people are we talking about anyhow?”

I was frustrated by these tales that continued to be discussed at our group meetings. It was obvious that our physicians were too young to have seen a case of active polio, let alone be able to recognize PPS. One morning, while I was volunteering at the Information Desk at the hospital, our hospital CEO walked through the lobby and I cornered him. I explained to him the need that had become evident, at our monthly group meetings, for educating area physicians about PPS. He, in turn, referred me to Dr. Robert Pyatt, who was the physician in charge of scheduling weekly staff Continuing Medical Education seminars. After many attempts, I was finally able to get an appointment to meet with him. At that time he said he could give me five to ten minutes from his busy schedule. I went armed with a video, printed material, and our membership list of seventy-five plus people. His first words to me were, “How many people are we talking about anyhow?” The information that I brought with me got his interest and our first meeting lasted more than a half an hour. After this, we worked together to orga-

nize a special program for physicians in order to educate them on post polio issues. Several recommendations for an appropriate speaker were made. Dr. Richard Bruno, from the Kessler Institute in Saddlebrook, New Jersey, agreed to come and lecture the staff in October of 1995. Personal letters were sent by Dr. Pyatt to our group’s personal physicians, and group members also encouraged their physicians to attend this seminar. Over fifty physicians and other allied medical professionals were present. Dr. Bruno remained and addressed our support group at our regular monthly meeting the following morning.

The overall physician reaction to Dr. Bruno’s presentation was very favorable. Our physicians now have a clearer picture of PPS as well as how to treat it. They recognize that PPS problems do exist and deal with us with more awareness and knowledge. There is also increased recognition of pain as well as sensitivity to anesthesia. Several members who have had to undergo surgery have found this to be particularly true. In each case during their pre-op evaluation these folks have met personally with the anesthesiologist. One member’s physician now monitors her more closely for upper respiratory infections. Two years ago, after I became short of breath on an overseas flight, my physician did a tremendous amount of research with the airlines in order to determine the ratio of oxygen to altitude. He has since prescribed daily use of a spirometer in order to increase my lung capacity. Physical therapists, as well as physicians, now recognize the need for rest and not over-exercising. The ancient theory: “No gain without pain” has become a thing of the past for post polios.

During our support group meetings we avoid non-productive “gripe sessions” but rather focus on educating ourselves. We have specialty speakers on various related topics such as orthotics, massage therapy, wheelchair exercises, acupuncture, pool therapy, nutrition, social security, and medication. Through these speakers, as well as learning from each other, we have become a well-educated group. By keeping ourselves informed we, in turn, educate our personal physicians. Members of our group are taking a more active role in their treatment by learning how to talk with their physicians and thus be active participants in their own health care. We feel it is up to us to keep abreast of information and research development through published material

as well as from the Internet. We often prepare, in advance, copies of information with highlighted areas applicable to our individual needs and a list of current health problems and how we cope or not cope. Our physicians are welcoming this input. One member, who was intimidated by physicians, has now learned that doctors are approachable and is taking more initiative and becoming more assertive in working with her physician to build a team. We have also expanded educational activities by lecturing a class of physical therapy students each semester at our Penn State local campus.

“Our physicians are welcoming this input.”

Dr. Pyatt is now Medical Director of the Cumberland County Health Network. He has continued to monitor our group members’ reactions and input about their improved medical care. He was so impressed with the outcome that he asked for my participation in the annual Continuing Medical Education Conference in San Diego. We participated in a mini-plenary session on “Patient Centered CE: Improving Quality and Outcome.” This was followed by a workshop with the focus on “Patient Centered CE.” Joan Headley, Executive Director of the International Polio Network in St. Louis, Missouri, also participated. We talked about how patients and their advocacy groups can play a critical role in CE. This was followed by a discussion of how this approach to CE can be used to empower other patients and other advocacy groups. Dr. Pyatt’s aim is to use our group and its accomplishments as a model to expand to other groups, e.g., diabetes, arthritis, multiple sclerosis, stroke victims, both locally and nationwide. People who are part of the problem can also be part of the solution. Finally, an educated patient is her/his own best resource.

Phyllis Ann Bailey, MSW, worked as a medical social worker at Johns Hopkins Hospital and in the Crippled Children’s Unit at General Hospital in Washington D.C. She was also a special education instructional assistant in Montgomery County, MD. Retired and living in Chambersburg, PA, she is the Coordinator of the Post Polio Support Group.

Amputee Support Groups: Patient Advocacy in Action

by Dee Malchow M.N., R.N.

When any crisis or significant loss occurs in an individual's life, there is a profound sense of loneliness and fear of the unknown. As the reality and the permanence of the loss settle in, one can 'know' that others have experienced this type of loss and yet feel afraid and alone in his/her own unique situation. People who undergo an amputation, death of a spouse or child, or other significant losses can experience these feelings intensely.

These emotions lead people to seek out others who have undergone a similar loss or experience. From these efforts, support groups develop. They meet many needs and can function in a variety of ways.

Probably the most common needs are for information and camaraderie, not necessarily in that order. There are so many things to learn about. How can one move on with life after so great a loss? To hear others share the facts but more, the understanding of the pain, fear and confusion, is of immeasurable value. One's experience is validated as others relate to the threat to identity, self esteem, and independence.

In Seattle, as in many other parts of the country, there is an Amputee Support Group at Harborview Medical Center, the area's Level I Trauma Center. It was established nearly 20 years ago for the express purpose of assisting with the amputation experience. This group meets weekly and is facilitated by a clinical nurse specialist who is, herself, an amputee. Other groups in the Northwest have emerged from this one in areas beyond Seattle.

As referred to above, there is typically a desire to find another person who has been down this road. In this instance, 'the road' is the experience of losing a limb. It is foreign territory to nearly everyone and a myriad of questions come to mind, including:

- what's going to happen to me now?
- how long before I heal, get a prosthesis, walk?
- are my feelings normal or am I going crazy too?
- who am I now? I don't feel as strong, capable, desirable, productive, etc. Am I still me?
- what are these 'phantom' feelings where my missing limb used to be?

Depending on how comfortable the members are with each other, a number of abstract as well as tangible issues may be raised in these groups. Recently, a male participant shared that he became tearful while singing in church last week. It stimulated a wide discussion about the grief process and individual variances involved in adjusting to limb loss.

Frequently, members will demonstrate their prosthetic limbs and answer questions about components, potential function, and suspension systems (how they stay on). Typically, people with new amputations are very grateful to have this type of exposure as they desire to become informed consumers in a high-tech field that they previously knew very little about. Pre-amputees are also encouraged to participate, as talking to others who are already moving on with their lives can defuse some of the fear of the impending surgery.

There is typically a desire to find another person who has been down this road.

The process of all this information gathering serves to establish the camaraderie. People come away from the group with comments like, "I don't feel so alone in this project now," and "It's good to know I'm not the only one who wonders what they did with my leg." People's feelings and questions are normalized as they listen and talk with others who have the same thoughts.

The Harborview Group was established by a nurse facilitator who knew from firsthand experience the great desire for information and support in adjusting to an amputation. Most support groups for amputees arise from this same awareness of need. Typically, the groups are not led by professionals but are lay persons reaching out to each other. Their approach to this goal can be varied.

Some groups have a structured style with formal presentations about common issues (medical, prosthetic, driving, sports, etc.). Typically, an informal question/answer session is included or fol-

lows these presentations. Other groups are traditionally informal and meet as almost a social gathering with regular lunches and annual picnics. Many groups are a mix of these two.

There is a national organization called the Amputee Coalition of America which has information on establishing, maintaining or locating a support group in a particular geographic area. It provides information that is valuable in forming new groups, setting up peer visitation programs, and even developing a newsletter.

The peer visitation program, a matching of trained visitors with similar amputations and lifestyles, is especially valuable as an outreach to new amputees. Besides the obvious benefit to the person with a new amputation, there is a heightened sense of purpose to his/her own loss as the visitor is now helping someone else recover.

Probably one of the choicest benefits of an amputee support group is the sense of empowerment experienced as patients learn from and share with each other. When a limb is removed, a feeling of helplessness or hopelessness may accompany it. Like most patients, a temporary dependence on the health care providers is necessary.

Someone has aptly stated, 'knowledge is power'. As the information and knowledge is shared, a realistic plan for recovery provides strength. Knowing what to expect minimizes the fear. People become survivors as they view others as survivors of a similar event. It becomes possible to get through the woods because others have done it and are willing to illuminate the path.

The important factor here is that one chooses to move out of the helpless patient role. Informed decisions put patients in charge of their medical care and give them the ability to gather further information from the health care providers. Decisions based on their own values and life experience replace those that might otherwise be made by doctors, nurses, therapists or prosthetists.

Dee Malchow, MN, RN, is a Clinical Nurse Specialist and Coordinator of the Limb Viability Service at Harborview Medical Center in Seattle, Washington. She is also an amputee as a result of a boating accident at age 19.

Thriving in a Small Community: The Ithaca Breast Cancer Alliance

by Joan Adler, M.A.

It was summer's end, 1993, and our dear friend Ned had just been diagnosed with breast cancer. Andi had been diagnosed three years earlier so took our shaken and near-paralyzed friend under her wing. She escorted her to the many doctors Ned needed to see and consult, and helped research and decipher the plethora of information necessary to make treatment decisions for Ned's particular type and stage of cancer. Andi, who had been diagnosed in New York City, had taken immediate advantage of a multitude of resources available there for support, information and referrals. Through Ned, Andi was struck by how scarce those resources were for women with breast cancer in central New York. Once Ned's surgery and chemotherapy were behind them both, an idea dawned, first with Andi and later with a small group of women she contacted. Somehow she found us, breast cancer survivors, and women who had been deeply affected by breast cancer in family members and friends.

...we would create an organization to respond to a serious need that had gone unmet.

We started as nine in January of 1994. Five of us had or were currently under treatment for breast cancer, one of us had a mother who'd been recently treated, and three of us had watched three, four, five, friends diagnosed within the last ten years. Two of us also had had serious scares. For eight months we met in Jackie's living room. First we told our stories. The local chapter of the American Cancer Society? "Ha! They told me to call back in 2 weeks after their local golf fund raiser ended." "Oh yea, they're rich — they never returned my calls, and when I finally got through a man answered — that was hard enough — but he knew

nothing about where I could find a wig or a prosthesis, nor did he offer to call me back with information." "I knew no one else who'd ever been diagnosed. My sister in D.C. had a friend who's sister had it, she lived in Arizona, so she's who I called." "I was desperate to speak to a woman with young children who'd had breast cancer. How do I tell them? What do I tell them? How do you get through chemo and get supper on the table?" Our community hospital has a support group for cancer survivors that meets once a month. "I needed so much more. When I first 'heard', I was living one hour at a time." "There are people there with all kinds of cancer. I needed so desperately to talk about breast cancer and how it was affecting me personally. It just didn't feel safe and I didn't have the patience or generosity to listen. Nothing seemed the same as losing a breast."

We also knew that we were the tip of the iceberg. We live in and around Ithaca, N.Y., located in Tompkins County, in the Finger Lakes region of upstate New York, a community of about 90,000 people. We learned that the breast cancer average in our area was about 6% higher than the state and national averages.

So over the next eight months, the Ithaca Breast Cancer Alliance (IBCA) was born. In retrospect, not one of us lacked confidence that we would create an organization to respond to a serious need that had gone unmet. Ithaca is a highly successful grassroots town. We'd all watched our food co-op become a supermarket, and especially on issues that concern women, there were revered, decades-old institutions (Planned Parenthood, Ithaca Rape Crisis, Task Force for Battered Women) that had grassroots beginnings.

Our first and primary task was to develop a mission statement that embodied our philosophy and goals. The heart of our statement evolved two chambers. After hours of discussion, it became all-important that IBCA welcome and support anyone with breast cancer regardless of the treatment path they chose. Within our small group, two of us had recurred after standard treatment, one of us was taking the macrobiotic route, and the rest were mixing it up, adding acupuncture, herbs, diet recommenda-

tions, and supplements to surgery, chemo, and radiation. The alliance, we decided, would give no advice but we would make every effort to provide sources of information and referrals to match the woman's interest and inclination. We needed to have this discussion because there were those amongst us with very strong biases. The other part of our mission was devoted to providing concrete support, information, and advocacy for people affected by breast cancer, including family and friends.

...with or without mone we were committed to providing some level of services.

The need for support was ever-present. Indeed, we saw each of our weekly meetings during those eight months devoted, in part, to filling that need for each other. It developed from our discussions that support needs would be multileveled. Whether it was the discovery of a lump, the statement by an MD that a mammogram was suspicious and further testing was indicated, or the news of a diagnosis, a prompt contact with a compassionate and informative resource is a great comfort. Thus a **Hotline** would be essential. For women newly diagnosed and undergoing treatment or for women who had recurred, a **support group** was needed, hopefully more than one, tailored to the phase of a person's recovery or progression. We decided that professionally facilitated groups would be wise because of the crisis component. We also wanted to make available short-term crisis counseling for individuals. Borrowing from the ingenuity of the AIDS movement, we also realized the value of a **buddy system**, which plumbed the practical side of support in the provision of research assistance, transportation to doctor's appointments, help at home during chemo, and a host of tasks as broad as one's imagination.

For the provision of information, we conceived of a well-stocked **resource center**

Thriving In a Small Community...

Continued from page 9

that would include cancer theory and treatments, both orthodox and unorthodox, books on healing, grieving, health, nutrition, meditation, women's stories and spiritual and inspirational readings. From experience we knew how difficult it can be to concentrate during a crisis, so we included videos, articles and pamphlets. Another crucial source of information would be an **information network**. Women need to talk. To facilitate this, the network would be a compilation of breast cancer survivors willing to talk to women who are newly diagnosed or who have recurred and are embarking on a new treatment. From each woman in our network, we would collect demographic information, type of cancer, practitioners used, treatments chosen, resources used, etc., so we would be able to best match a caller's needs. For example, if a woman about to undergo a mastectomy was also considering reconstruction, we'd connect her with women in our network who'd made that choice. We would do the same whether the issue was age, work, children, sexual orientation, etc. Another planned vehicle for information dissemination was a quarterly **newsletter**. It would not only inform the community of IBCA's existence and activities, but by printing our members' stories, hopefully cut through the isolation and stigma many women with breast cancer still feel, and, hopefully, replace despair with hope, shame with valor. We would also interview local practitioners, and reprint current news briefs and articles on current breast cancer research and treatment.

After four months of intense planning we set out, over the next five months, to realize our goals. We introduced ourselves to the community through newspaper interviews, fund raisers and an open public meeting. This pre-publicity was vital for assessing the need for our services and garnering critically needed volunteer, financial, and political support. We began furiously writing for grants, but with or without money we were committed to providing some level of services. We were fully prepared to house our resource center in a spare bedroom and answer hotline calls from our kitchens. We were buoyed initially by quickly receiving a community award from our public library to begin stocking our library.

And, almost immediately, five therapists volunteered as support group leaders and crisis counselors. Volunteers also came forward and endured lengthy training sessions to

staff our hotline, and to become buddies. But major money, for an office, basic equipment, a phone line, let alone a meager part-time salary, eluded us. We soon discovered, and live with the radically unfair reality to this day, that funding for services for women with breast cancer does not exist. Almost exclusively, money is available for research, early detection and education about early detection, but there is nothing once a woman is diagnosed. The nature of breast cancer — its incurability and treatment — create significant social/emotional needs that are not heeded. The emphasis on early detection is not wrongly focused on survival, but the aftermath of detection is generally trauma, revolving around mortality, disfigurement, sexual identity and potential impact on family stability and relationships. In the midst of this whirlwind a woman must make treatment decisions, a laborious process. Decisions must be made even if one follows a strictly orthodox route. By and large, the experts only present one with choices and recommendations, not certainties.

...funding for services for women with breast cancer does not exist.

We were finally able to procure \$5,000 in seed money from a local funding organization that enabled us to open an office in September of 1994. Since then, through the advocacy of our local health planning council, we get a small stipend from our county, and have been awarded a legislative grant through our state assemblymen. We have also received small grants from the Susan G. Komen Foundation, specifically for education on early detection. Alion's share of our revenue has come from local fundraising. In 1998 we have a \$94,000 budget and between 50-60% must come from donations. Our most successful ongoing efforts have been a yearly walkathon, for which we've also cultivated a healthy list of local corporate sponsors, and membership drives. A stupendously successful one-time event was a 'small quilt' auction that we organized in collabora-

tion with a local quilters guild. But fundraising is exhausting, particularly with a staff of three, who are responsible, not for development, but for running the organization, and a Board that, albeit active, also all have full-time jobs. We are currently conducting a state campaign involving all our legislators, the speakers of both houses and the governor to procure some hard money.

IBCA has had nothing but growth spurts since 1994. All of our services are up and running and continuously expanding. We have an executive director, a volunteer coordinator, and an outreach worker to all of whom we can only pay part-time salaries. From 1996 to 1997 the totals for our first time clients jumped from 79 to 179, our total clients from 104 to 222, office and telephone consults with clients from 505 to 1029, resource center use from 441 to 1181, and use of our services by health care professionals from 22 to 53.

A final phase of our work at IBCA involves the advocacy we provide. Not only do we advocate for individuals through our buddy system, but through the respect we've earned from the cancer-medical community, we've been invited to relay information garnered from our clients that they may not hear directly. We've conveyed, for example, that our clients have had difficulty getting referrals for second opinions and about the difficulty of hearing a diagnosis on a Friday. On a state level, members of IBCA serve on the advisory board of Cornell University's Breast Cancer and Environmental Risk Factors program that investigates pesticides and chemical toxins in our state's soil, air and waterways. And, nationally, two of our members were selected in 1996 as consumer reviewers on the National Review Board of Breast Cancer Research that had jurisdiction over \$75,000,000 in federal funds.

For additional information, please contact:
The Ithaca Breast Cancer Alliance
P.O. Box 853
Ithaca, New York 14851
(607) 277-9060
e-mail: DIAD95@AOL.com

Joan Adler, HA '89, is founding member and Board President of IBCA. In addition, she works for Planned Parenthood and remains an active member of the Moosewood Restaurant collective in Ithaca, New York.

Grass Roots = Cutting Edge?

by Brian on Christopher Street

I am not quite sure when the original HIV-Support Group on the Internet began, but as one would expect, the group was primarily gay men with a small group of heterosexual hemophiliacs and parents of HIV infected children. In 1995 the service provider realized that the diversity of the group had broadened. In an effort to preserve the fundamentals of the group, it became apparent that the logical decision was to spin off a second group. This new group would be a closed group exclusively for Gay Poz Men. The members could feel safe discussing not only treatment issues, but the politics of HIV, comparing experiences with insurance and SSI /SSD, the challenges of dating practices, sexual options, disclosure to their family of HIV status, and in some cases their sexual orientation. As with any support group, non-topic issues will arise and they are openly shared in a "safe" environment.

This in no way suggests that very similar challenges do not confront the entire HIV community. One must keep in mind that this service was founded by a gay man, offered at no charge to all, and it's a private e-mail service. "Political correctness" is not a goal or a benefit to subscribers. As a gay man living with HIV I can only share a facet of my perspective of Internet Support.

When I first subscribed approximately nine months ago, I had great trepidation about daily wading through the sad messages from people suffering with opportunistic infections, side effects from toxic medications, personal crises, and witnessing subscribers venturing into territories never before explored by patients or the medical establishment.

With time I noted the patterns that inevitably occur within all groups of people. As you might expect my observations and their patterns were all predictable. I tend to dissuade those who disagree with my posture, though even I realized that in "raw cyberland" you can not tell exactly what people are saying, without the benefit of emotion, expression, tone of voice, gestures, etc. More specifically I recognized exchanges involving the tweaking of medicine combos (the term "cocktail" comes to mind, which I refuse to use in reference to medicines). When the need to change their combo occurs and sud-

denly something goes awry, subscribers would report unforeseen rashes, fever, nausea, dizziness, shortness of breath, whatever. Usually in less than 12 hours one of the 500 subscribers would recognize the side effects he had already lived through. With that firsthand experience he would share the fine tuning of medications he and his physician had adopted. Needless to say, it is not 100% accurate but it sure can reduce the number attempts to

...you have a staff of dedicated researchers, 'the likes of which you've never seen before.'

blindly try different combos. One must remember in the case of HIV treatment (which is all experimental) the medical field learns new information on a weekly basis. This can include identifying new or enhanced benefits, but severe side effects as well. More than once I have witnessed a member taking data from another subscriber's experience to his physician, only to have the physician shake his/her head in astonishment.

Frequently the physicians readily admit that their patients know more than they do. Subscribers compare their histories, viral loads, T-cells, but other exchanges can be as simple as recipes for chronic diarrhea. After trying a dozen medications with no success, alternative treatments have a very meaningful place as well.

When you look at the demographics of this community, it's quit dynamic. Combine above-average education, many formerly successful professionals/executives, computer access, Internet savy, hours a day of availability, the huge quantity of cutting-edge information on the Net, and you have a staff of dedicated researchers, "the likes of which you've never seen before." Realistically speaking, a practicing HIV physician cannot keep up with developments on both the scientific level and the exchange of daily feedback regarding

unforeseen reactions to the "onslaught" of new drugs rushing to a desperate market. This is not to say "flame wars" (Internet jargon for cat fights) do not occur with regularity...misunderstandings, overly sensitive individuals, house-bound patients without much of a life can and do contribute to a "bumpy ride." For those with more time on their hands then they reasonably need it can be extremely informative as well as entertaining.

With a large percentage of the subscribers being middle-aged, some symptoms are confused with HIV illness rather than the natural aging process. These are pertinent issues that need addressing as much as the HIV related issues. When a subscriber loses a loved one, be it a significant other or a grandmother, the support and reaching out of the group can be overwhelming. I have yet to observe what will go on when one of the subscribers passes... "tears and keyboard" come to mind.

The primary definition in the Merriam Webster Dictionary of "grass roots." is: "the very source or foundation." For me my daily interaction with the "HIV POZ group" is at the core of my existence...be it for better or worse.

Brian is a retired 50-year old man living with HIV. He was diagnosed in 1985, when the antibody test first became available.

Congratulations...

Continued from page 15

objectives. At Sarah Lawrence, she says, "I learned to analyze issues from multiple points of view, and acquired many of the skills I will need as an advocate to keep up with the changes that are inevitable in the health field. Experiences garnered in internships have been invaluable. I also learned to read faster, and use the Internet!" After a "physically exhausting" vacation and a final internship at Pfizer, Inc., she'll be looking "like all graduates, for a permanent position."

Self-Empowerment: The Independent Living Movement

(Editors Note: This article originally appeared in slightly different form in *ALIVE* magazine and is reprinted here by permission. The author has modified it for publication in the Bulletin.)

by Lisa Tarricone

“No one can make you feel inferior without your consent.”

Eleanor Roosevelt

In the Beginning — Birth of the Independent Living Movement

When Ed Roberts entered the University of California at Berkeley in 1962, the headlines of a local newspaper announced his arrival: “Helpless cripple goes to school.” But to Roberts, a post polio quadriplegic who slept in an iron lung at night, Berkeley would be his message out to the nation, heralding a new disability rights movement built on self-belief, determination, and independence.

“Independent living had become a full-fledged civil rights issue...”

At Berkeley, Roberts, in unison with other disabled student activists, started the Physically Disabled Students Program (PDSP) to address the rampant inaccessibility on campus, by setting up an advocacy department to assist disabled students with accessible living arrangements, benefits, and services. Utilizing the principles established by PDSP as an advocacy tool for disabled students, the Center for Independent Living was created in 1972 as a parallel program for disabled people in the community. *Independent living* had become a full-fledged civil rights issue, prompting enactment of the Civil Rights Act for the Disabled (Section 504 of the Rehabilitation Act) in 1973. This legislation prohibits discrimination against disabled persons in programs, services and benefits that are Federally funded, and set the foundation for future generations of disabled individuals to have access to and be able to engage in life pursuits not

afforded previous generations of disabled individuals. By 1978, under Rehabilitation Act Amendments, the Federal Government began to provide funding to establish Independent Living Centers (ILCs) in virtually every state and U.S. territory. To date, over three hundred Independent Living Centers, or ILCs, exist nationwide based on the tenants of self-empowerment that Roberts established for himself and his peers.

The Philosophy of Independent Living

Independent Living is based on the belief that persons with disabilities have the same basic human rights as persons without disabilities to participate in and contribute to community life. The philosophy behind the Independent Living Movement is defined in terms of the *control* that a disabled person has over his or her life. As such, the ILCs ideally and mostly are operated by disabled people serving as models and experts in running their own self-help programs. Independent Living is a drastic shift away from the view that disabled is equivalent to sick and dependent — that persons with disabilities need to be looked after, cared for, and pitied, because they’re disabled. Independent Living’s fundamental principle is **empowerment** rather than “care”. In the words of Ed Hooper who writes for *The Disability Rag* magazine: “If we agree that the status quo is unacceptable, we must affect change, or start wheeling back to our place in society’s shadows and corners.”

Westchester Independent Living Center — Services, Outreach, and Advocacy

The Westchester Independent Living Center (WILC), located at 297 Knollwood Road in White Plains, New York, is part of the national network of Independent Living Centers and serves as both a resource and referral center for persons with disabilities who reside and/or work in Westchester County, New York. WILC’s services are non-residential, non-medical, and delivered by qualified individuals with various disabilities. Executive Director Joseph Bravo says that optimally the services offered at WILC should provide the incentive for disabled consumers to eventually advocate for themselves. “I would like to see our disabled constituency

become more proactive in making their voices heard and their needs known,” states Bravo. He stresses the importance of “personal responsibility” and leadership development to consumers: “No one else will state your case for you, not even WILC. In the meantime, maximize what is available and have a plan to move on with your life.”

What is available at WILC are a broad range of programs and services provided free of charge to any disabled individual and/or his/her family members. The programs that follow are offered without regard to age, sex, ethnicity, or religious affiliation, and additional services can be custom designed to meet individual or family needs.

- **Peer Advisor Advocacy Program:** The Center provides individual and group counseling services, offering individuals with disabilities emotional support and practical advice on issues such as educational and vocational opportunities, housing, adaptive equipment, and financial management.
- **Benefits & Entitlements Services:** Assistance is provided to help consumers understand what resources are available to them and how to effectively make informed choices regarding: Social Security Disability, Supplemental Security Income, Medicare, Medicaid, food stamps, and work incentive programs.
- **Information and Referral:** The Center provides information on, and referrals to, services available for individuals with varying disabilities, and in addition, offers a resource/legal library on issues related to disability.
- **Mental Health Advocacy Program:** This service supports the empowerment of individuals labeled mentally ill by helping them identify and make quality of life choices, increasing opportunities in the community, and by providing advocacy and benefits counseling to mental health recipients/consumers/survivors throughout Westchester County.
- **Client Assistance Program (CAP):** WILC serves as the regional office for this program, servicing seven lower Hudson Valley counties. CAP provides information and advocacy services to individuals trying to access vocational and rehabilitation

Family Caregivers Take Charge

(Editors Note: This article was compiled by Irene Selver from material provided by the National Family Caregivers Association.)

“Anyone can become a caregiver at a moment’s notice” says Cindy Fowler, co-founder of the National Family Caregivers Association (NFCA). Though the circumstances are different for each individual caregiver, many share the same concerns, questions, fears and sense of isolation. “We all hurt the same way, feel the same guilt,” says Suzanne Mintz, NFCA’s other co-founder. “We all want our loved ones to be well, we all want a miracle. We all experience frustration more than other people do and we all start to feel invisible and isolated. We rarely get the help we need. What we have in common are our emotions.” Angry at being so isolated and ignored in their challenging role as caregivers, these two friends channeled their frustration and began the National Family Caregivers Association in 1993.

NFCA is a not-for-profit membership organization whose mission is to improve the overall quality of life of America’s more than 25 million family caregivers. As family caregivers focus on their loved one’s needs, NFCA focuses on family caregivers. It is the only national organization serving all family caregivers, regardless of their relationship to the person receiving care or the specifics of the medical situations they confront.

Membership to NFCA is open to family caregivers, their friends, and the professionals and institutions supporting them. Through its services in the areas of education and information, support and valida-

tion, public awareness and advocacy, NFCA strives to minimize the disparity between a caregiver’s quality of life and that of mainstream Americans.

Family caregivers are known to provide approximately 80% of all the home care in this country. Three-fourths of all caregivers are women. According to surveys conducted by NFCA and backed by other studies, caregivers tend to neglect their own health, developing what Suzanne Mintz refers to as “Caregiver Disorder”. She points out

*Taking care of yourself
as a Caregiver...
is a selfless act.*

that as family caregiving is about chronic, long-term care, occurring mostly in the home behind closed doors, it goes unnoticed in our current health care system. As caregivers struggle to create as good a quality of life for the family as possible, there is a loss of normalcy that needs to be recognized and addressed. “‘Caregiver Disorder’ needs to be recognized as a very real syndrome — one that is treatable with education, proper psychosocial and medical attention, and an appropriate level of help and support from others. But it can’t be treated until caregivers, the health care community, policy makers and the general public recognize its existence. Caregiving

needs to lose its cloak of invisibility.”

Quoting the founders of NFCA, “Taking care of yourself as a Caregiver is not a selfish act, it is a selfless act”, the organization provides a variety of services which include: a quarterly page newsletter, TAKE CARE! Self Care for the Family Caregiver; a Caregiver to Caregiver Support Network; the NFCA Speaker’s Bureau; the NFCA Caregiver Member Survey Report; a new Bereavement Program for former family caregivers; Cards for Caregivers; and the National Family Caregivers Week Celebration, to raise public awareness and caregiver consciousness. Also available is NFCA’s resource guide, *The Resourceful Caregiver: Helping Family Caregivers Help Themselves*.

From their own personal experiences as family caregivers, Suzanne Mintz and Cynthia Fowler co-founded the National Family Caregivers Association around the following Principles of Caregiver Self Advocacy:

- Choose to take charge of your life.
- Honor, value and love yourself.
- Seek, accept and at times demand help.
- Stand up and be counted.

For additional information or to receive a membership packet, please contact: National Family Caregivers Association

10605 Concord Street, Suite 501

Kensington, MD 20895-2504

(301)942-6430 (800)896-3650

Fax(301)942-2302

email: INFO@NFCACARES.org

web site: WWW.NFCACARES.org

Self-Empowerment...

Continued from page 12

benefits and services through both government and private programs.

- **Traumatic Brain Injury Services:** Information, referral, and services are provided to individuals with traumatic brain injury and their families. In addition to assisting consumers with TBI with relocation opportunities, this program helps to identify and address the gaps that exist in the continuum of care for TBI in the region — from coma to re-entry into the community.
- **Minority Outreach & Integration Project:** This project seeks to build lasting bridges to the African-

American and Hispanic communities in Westchester by ensuring that minority consumers have full-range access to the resources available for people with disabilities and equal opportunity to participate in all aspects of community life.

- **Social Integration Program for Visually Impaired Elderly:** Community specialist and older adult volunteers assist visually impaired clients, 55 and older, with activities linked to maintaining or re-establishing social integration.
- **Mentoring Program for Individuals who are Legally Blind:** The Mentoring Program provides individuals who are legally blind with peer assistance to challenge and inspire them to pursue a realistic goal and to strive for a new level of personal satisfaction.

Westchester County is home to approximately 150,000 persons with varying disabilities. WILC’s Systems Advocacy Services will take necessary actions to make systematic changes on community issues that effect people with disabilities as a group. “We need to collectively work toward changing our communities in order to positively affect the quality of disabled individual’s lives,” affirms Joe Bravo. For more information about what you can do to get involved and/or participate in any of the services that WILC offers, contact The Center at: 914-682-3926.

Lisa Tarricone is the Public Relations Coordinator for Independent Living Services for the Westchester Independent Living Center, and a freelance writer.

Rally for America's Health

by Diana Westgate Armstrong

Rousing music from Sousa and Springsteen filled the air above the West Lawn of the Capitol on March 13, 1998 as *Youth for America's Health! (yah!)* began its historic mission to unite American youth around the issue of solving our nation's health-care crisis. Bound by the universal principle that **Every person has the right to health care, yah!** planned its *Rally for America's Health* and lobbying day to bring attention to the current crisis of the medically uninsured.

yah! was formed by the American Medical Student Association (AMSA), the nation's largest and oldest independent medical student organization that represents nearly 30,000 physicians-in-training. AMSA's *yah!* also represents a coalition of concerned individuals and organizations dedicated to ensuring that all people achieve their right to health care. The coalition promises to forward this goal by promoting education and activism designed to increase the quality and accessibility of health care.

Quotes from the organization's primer/brochure take the following stands:

"It is time for the United States to recognize health care as a human right. The American Medical Student Association, in forming *Youth for America's Health! (yah!)*, is taking the first bold step toward addressing our country's health care injustices. Please join us."

"The United States must recognize Universal Health Coverage as a basic human right and amend the Constitution accordingly — for this is not merely the will of the American people, but more significantly, an innate human right."

Primer and rally flyer references to statistical findings on America's uninsured include the following:

- "44.8 million Americans were uninsured for the full six months between January and June, 1996." *That's about one out of every five Americans.*
- "87% of the uninsured reside in a household with a working adult." *It could be a parent or a relative.*
- "11 million were children." *It could be you.*
- "More than 17% of Americans lack any form of health insurance according to the Medical Expenditure Panel Survey in 1996."

AMSA's *Rally for America's Health* was held in conjunction with its 48th National Convention in Washington, D.C. Approximately 250 medical students, representing 70 medical schools, participated in the event which called on Congress to provide access to health care for every American. Rally organizers and speakers urged all participants to increase awareness of the medically uninsured by supporting the following AMSA Amendment which calls on Congress to enact universal health care coverage by March 13, 2008:

...they all urged getting involved politically on the community and national levels.

THE AMSA AMENDMENT:

Section 1. Health care is an essential safeguard of human life and dignity, and there is an obligation for the federal government of the United States of America to ensure that every citizen is able to realize this fundamental right. On or before March 13, 2008, the United States Congress by law shall enact a plan for universal health-care coverage that permits every citizen of the United State of America to obtain health care on a regular basis.

Section 2. The Congress shall have the power to enforce this article by appropriate legislation.

"Of all the forms of inequality, injustice in health care is the most shocking and inhumane." — Martin Luther King

"The threat of illness and the absence of guaranteed health care shackle us, deny us the liberty to pursue our dreams or threaten our right to life. Neither we nor our parents or children can receive the right to happiness while we live in fear of the absence of a basic right to health care, should we or those we love fall ill." — American Medical Student Association

Speakers during the two hour rally included Senator Paul Wellstone (D-MN),

Representative Bernard Sanders (I-VT), Dr. Douglas Robins (co-chair of the DC Physicians for a National Health Program (PNHP), Jennifer Jones (co-founder of Students Together Ending Poverty (STEP), Kavita Pate (National President, AMSA), and Robert Chisholm (Legislative Affairs Director, AMSA). In speaking to these future physicians and their coalition, they all urged getting involved politically on the community and national levels. This involvement would prove to be the most influential in changing policy for securing humane, affordable and accessible health care, they stressed.

As the rally ended, the students organized into regional lobbying teams and set out with bright AMSA posters and a plan to spend the rest of the day visiting congressional offices. Rally facts sheets urged lobbying and support for the following pending federal legislation and for AMSA's 1997-1998 National Project, *Stamp Out Smoking*.

- **Patients' Rights:** *Health Insurance Bill of Rights Act of 1997 (H.R. 820); Managed Care Consumer Protection Act of 1997 (H.R.337).*
- **Access to Care:** *National Health Service Corps Scholarship Program Incentive Act (S. 1286); National Health Service Corps Scholarship Program (H.R.2998); National Health Service Corps Scholarship Program Incentive Act (H.R.2951).*
- **Diverse Physician Workforce:** (oppose H.R.1909,S.950) and support *Racial and Gender Preference Reform Act (H.R.2079)* as an alternative if affirmative action is ended completely.
- **Tobacco and Smoking Issues:** *Stamp Out Smoking* will mobilize medical students to tackle the multifaceted aspects of smoking and tobacco use in this country. Each AMSA chapter will work to reduce smoking and tobacco-related deaths in their communities and will work to change governmental policy.

Diana Westgate Armstrong will graduate from the Health Advocacy Program in December, 1998. This summer she will spend six weeks as a fellow in the Government Affairs Office of The March of Dimes in Washington, D.C.

Joan Marks to Retire

by Deborah Hornstra, M.A.



The Health Advocacy Program recently announced the impending retirement of the program's director and founder, Joan Marks, at the close

of the current academic term. As Marks prepares to depart after 18 years at the program's helm, she wants to make one thing clear: "It's been a fabulous privilege to direct this program. It's a different, committed, caring, imaginative program."

Marks will also step down as director of the Human Genetics Program, which she has directed since 1972. A longtime resident of New York City, Marks is looking forward to spending less time in Bronxville and more in Manhattan. She'll also undoubtedly be enjoying her new grandchild (number 5).

It's a big change for the Health Advocacy Program, which has been under Marks' direction since its inception in 1981. A search committee has been established to find a new director, and Marks is convinced

the transition will be a smooth one. "The important thing," says Marks, "is that there be continuity, support for continuing the program from the College's new President (Michele Myers, the former President of Dennison College in Ohio, who is soon to succeed Alice Stone Ilchman). And we have that support: the commitment to the program has been made."

Marks recalls when the Health Advocacy Program started out, as an idea being considered by leaders in the field of hospital patient advocacy in her living room. Those friends included Ruth Ravich, Anne Cote and Norma Shaw Hogan. "We talked about whether patient advocacy was a viable profession," Marks remembers. "We talked about which disciplines would need to be included in the curriculum. We always wanted to make it broader than just patient representatives and ombudsmen."

Terry Mizrahi was brought on board early in the formative stages to teach Health Advocacy I, which she still does. Margaret Keller referred herself to teach health law (she had seen an article about the program in Science magazine). Marsha Hurst was also brought on early, and Marvin Frankel was already teaching in the Human Genetics program. This was the genesis of the Health Advocacy Program.

From the beginning the program attracted a small but select group of students.

"No one who graduates from this program is boring," says Marks emphatically. "We target people who are something different, and we get the most unusual students." Marks admits the program might be a bit bigger, but "we're interested in quality, not quantity. Our faculty have always considered the Health Advocacy students among their most exciting students."

As the Health Advocacy Program moves forward under new leadership, Marks is confident it will grow and evolve. "This program has enormous undeveloped potential. The new director will be a direct, dynamic, take-charge person. They will have a deep interest in health care, a deep commitment to the concept of patient advocacy, and good teaching skills. And most important, they will have ideas and energy and vision, which they will use to develop the program to meet the challenges of the future."

The Health Advocacy Program owes an enormous debt to Joan Marks. She had a unique concept: an educational model that would create voices for patients in the health care system. The important work being done all over the country by graduates of the Health Advocacy Program is her legacy.

Congratulations, Class of 1998

This academic year Sarah Lawrence will graduate five more patient advocates, and as usual the group is unusual, diverse, committed and innovative.

Adrienne Wilbrecht was living in Minnesota, fresh out of college with a major in public health and biology, when she found Sarah Lawrence College on the Internet on a History of Medicine chat line. By that fall, she was in New York, enrolled in the Health Advocacy Program. She was impressed by the many different experiences students bring to the program, and in the course of coping with a new city, she says, "I also learned to advocate for myself." Her principal interests are managed care and primary preventive care for women and adolescents. She is currently working in Florida in a well-woman program funded by Planned Parenthood, and as a Patient Representative in the Emergency Room of a local hospital.

Karen Crimmins, who had been both an elementary school teacher and a retail real estate consultant, saw a need for advo-

cacy when various family members became patients. When she read in the newspaper about Sarah Lawrence graduation and noticed "Health Advocacy" as a field of study, she changed careers. Out of school for a long time, she found being a graduate student "a great growing process. I learned so much from classmates, learned to accept myself and others. To understand and listen to others is a great tool for an advocate." Her field work included researching state regulations on Medicare for HMO's in the tri-state area, and she is particularly interested in changing the attitudes of legislators and public servants toward patients. She'd like to work in public policy and says, "This program has prepared me to look at things creatively, and my approach to a job is the same. While I'm looking, I'll be catching up with three years of dirty dishes."

Karen Wexler was an actress, but had thought about a career in health, and being a patient representative appealed to her. She has found that Health Advocacy "welcomes people from all walks of life and make a

place for them. I could focus on skills that I already had — from arts and literature — and discovered that these could work in another field." She is thrilled to have just been hired as a Patient Representative at Memorial Sloan-Kettering.

Also expecting to work as a hospital patient representative or as a health educator is **Marsha Einhorn**, a former teacher with eleven years experience in health care. Interested especially in patient/family education and clinical ethical issues, she believes her education at Sarah Lawrence "has given me a unique and valuable cluster of skills."

Rebecca Sullivan was a practicing advocate, but in a different field: she managed the careers of classical musicians and worked as a volunteer on the development staffs of several cultural institutions in New York City. As a health advocate, she's interested in creating access to quality services for vulnerable populations, such as women and children and the mentally ill, and in the promotion of rational public policies to achieve these



Health Advocacy Program
1 Mead Way
Bronxville, NY 10708-5999

Address Correction Requested

HEALTH ADVOCACY BULLETIN