

HEALTH ADVOCACY BULLETIN

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Educating for Advocacy:

Using Patient Voice to Construct a Model of Theory and Practice

By Constance Peterson, HA '94
Faculty, Health Advocacy Program

[In September Constance represented HAP at the conference, "Patient and Community Voices in Professional Learning: Building a platform for change," Clare College Cambridge, UK. This is an abridged version of her conference statement]

While the past few decades have brought great advances in medicine and technology, these advances have occurred within a healthcare system comprised of complex bureaucracies organized more for the benefit of service providers than patients, families or consumers. Health profession educators are in a unique position to question whether these trends best serve patient interests by using education to move the system to a more patient centered focus. The delivery of quality healthcare in a patient centered system is dependent on attention to patient voice; issues of empowerment, autonomy, access and education are integral to the care itself.

Education of the health advocate is distinguished from other health professional education by our attentiveness to the centrality of voice. HAP students come to understand the patient's voice through privileging their own experience, field-work contact with patients and providers, and integration of voice into a core curriculum. Students are challenged to find their own voice as health advocates and to acquire essential knowledge about themselves by engaging in self-reflection and becoming more comfortable with ambiguity, uncertainty and multiple perspectives.

Central to the curriculum model used

in the Health Advocacy Program (HAP) at Sarah Lawrence College is the concept that a crucial part of the learning experience should take place outside the classroom in the real world of hospitals, agencies and organizations where the patient's voice can not only be heard but listening can take place within the context of the patient's experience. In these settings students can consider the complex and negotiated nature of healthcare interactions by observing experienced professionals as they work with patients, clinicians, administrators, consumers, and community organizers. These internships facilitate learning and professional growth

through a theory-practice dynamic that affords students the opportunity to acquire skills such as empathic communication, negotiation, conflict resolution and collaborative problem solving.

The classroom then becomes a place where students are encouraged to expand the scope and diversity of their experiential and academic knowledge by exploring the historical evolution and the broad social and cultural forces that shape patterns of health, medicine, disease and illness; they learn to examine the social implications of new scientific discoveries, power inequities and the ethics of provider/patient relationships.

THE MERGERWATCH PROJECT

By Sheila Reynertson, HAP student

In the Summer of 2006, I worked with an organization called the MergerWatch Project, an affiliate of Community Catalyst, a national consumer advocacy organization. Founded in 1997, MergerWatch originally assisted grass roots advocates in protecting contraceptive services threatened by religious/secular hospital mergers. Today the organization advocates for patients' rights to health care unencumbered by a wide range of religiously-based restrictions. MergerWatch continues to address hospital mergers but also has interest in issues such as pharmacy refusal clauses, emergency contraception restriction in Catholic emergency departments, and physician restrictions regarding access to reproductive technology for homosexuals.

It is a small organization with big ideas

and important connections to progressive organizations such as NARAL, Women's Law Center and ACLU. Lois Uttley (project director) and Reena Singh (director of advocacy) work together writing grants to fund specific initiatives, fielding calls from individuals who are denied health care for religious reasons, and fostering coalitions among advocates across the country.

At MergerWatch I was asked to look into the legal and ethical implications of emergency contraception restrictions in Connecticut's Catholic Church-sponsored emergency departments. I began to research the situation and specifically to determine the extent to which the federal Emergency Medical Treatment and Active Labor Act (EMTALA) could be used to address this religiously based policy. Throughout most of the summer I worked on a white paper examining how these contraception restrictions could be in violation of EMTALA and, if so, how best to address a remedy. Lois gave me feedback on my work and opened doors for me to discuss the research with MergerWatch board members. Periodically I was asked to summarize my findings on conference calls with Connecticut advocates for rape victims and reproductive rights. Most re-

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Lois Steinberg, HA '00, an Advocate for Seniors, is named a Civic Ventures Purpose Prize Fellow

Lois Steinberg was named one of 55 Purpose Prize Fellows from around the country for her work as founding Director of Westchester S.O.S. Medicare (Seniors Out Speaking on Medicare), a program of the Medicare Rights Center (MRC)—a non-profit, New York City-based, national consumer service organization.

“Our goal is to empower people to help themselves and others get the care they need when they encounter the health care system,” according to Lois, who is working on two new Westchester MRC programs: The first is a series of “health literacy” workshops and the second is an exploration and promotion of “aging in place” programs for Westchester seniors.

Health Literacy Workshops

Functional health illiteracy, has serious health and economic consequences across all socio-economic categories. Research sponsored by the Institute of Medicine found that almost half of American adults have low health literacy skills and nearly half of adults over 65 performed at or below the lowest health literacy level.

Seniors Out Speaking on Medicare (SOS Medicare) has been developing workshops to provide health education and advocacy training to enhance the level of health literacy—and thus health empowerment—in the community. The workshops will deal with such issues as how to find a good doctor, how to get your doctor to listen to you, what should be included in your annual physical, understanding your health care coverage, and how to navigate a hospital stay.

SOS Medicare has a strong track record in Westchester: between 2005 and 2006 SOS Medicare volunteers conducted over 120 presentations to help over 6,000 County residents understand the new Medicare prescription drug benefit. These volunteers also helped another 2,000 people enroll in a drug plan. They

received one of the Volunteers of the Year awards from The Volunteer Center/United Way for this work.

Living at Home: Aging in Place Program in Westchester County

As the baby boom moves into its senior years, and at the same time the fastest growing segment of the population are those over 85, we see an increasing need—and desire—for programs to help seniors who wish to stay in their homes and communities. Yet, however simple it sounds, “aging in place” is not simple at all.

The “Living at Home” project will develop a model of an aging in place program that reflects the core needs of communities in Westchester and yet is flexible enough to adapt to the unique needs of the wide range of communities within the County. “Living at Home” will build

on County resources by focusing on education and advocacy as the connecting link to help residents access and get the most out of existing local services.

“Living at Home” is a collaboration of the Westchester Program of the Medicare Rights Center and the Health Advocacy Program of Sarah Lawrence College. This collaborative project is working on two fronts: developing a core resource center that will help communities build capacity to implement a “Living at Home” program; and, with support from the Benedict Foundation, reaching out to communities in Westchester with aging populations to educate residents about the concept of “Living at Home” communities.

For additional information or to get involved, contact: Lois Steinberg loissteinberg@verizon.net or Marsha Hurst mhurst@sarahlawrence.edu.

Healthcare-NOW! Internship

by Helen Lefkow, HAP student

In a small office in downtown Manhattan, several diligent volunteers are fighting for a very big cause – Single Payer National Health Insurance. The office is that of Healthcare-NOW! (HN), a national organization that works with over 90 local affiliates in towns and cities across the United States. Healthcare-NOW! affiliates come in many forms – unions, faith-based groups, health professional organizations, physicians, medical students, small businesses and health activist groups – but they all are advocating for the same goal – a single payer healthcare system that is accessible and affordable for all. HN also works closely with Physicians for a National Health Program and Congressman John Conyers, sponsor of House Resolution 676, the bill for a National Health

Insurance Program.

HN began three years ago as an offshoot of the Women’s International League of Peace and Freedom. HN’s founder and National Coordinator, Marilyn Clement, is the former Executive Director for the Center for Constitutional Rights and a longtime human rights activist who began her career working with Martin Luther King in the 1960’s. Marilyn travels the country, speaking to audiences about the need for a single payer system and how it would work. With a shoestring staff and a budget that depends entirely on donations, HN passionately believes that a single payer system can become a reality in the near future.

HN’s latest educational piece is a twelve-page question and answer booklet entitled “Improved Medicare for All (Single Payer),” which responds to the most common questions and beliefs about a single payer system. “Improved Medicare for All” spells out in a clear, concise fashion how wasteful and inefficient our current system is, why and how single payer is the answer, and debunks myths about a national health insurance system (it’s socialized medicine, we don’t have the money to do it, limited benefits, etc). To get copies of the “Improved Medicare for All” publication, and to learn more about Healthcare-NOW!, visit their website at www.healthcare-now.org.

www.slcc.edu/health_advocacy

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Letter from the Director

By Marsha Hurst

Periodically I am prompted to revisit the Mission Statement drafted by the Health Advocacy Program's Strategic Planning Committee in April 1999 soon after I became Program Director. The mission and goals remind me that the three pronged goals of our master's program are still the underpinnings that support our work: educating students to serve patients, families & health consumers; serving the community; and contributing an advocacy perspective to the public discourse. In other words, while we sit in our beautiful campus home, in the intellectual midst of liberal arts exploration and expression, we cannot fulfill our mission if we allow this context to be our "ivory tower."

The Health Advocacy Program's founding was almost coterminous with the founding of an association specifically for hospital-based patient advocates (now the Society for Healthcare Consumer Advocacy, a membership organization of the American Hospital Association). Health advocacy, however, has expanded into different roles, settings, organizational structures, and different ways of promoting health, protecting rights and serving patients. So too has the Health Advocacy Program expanded its involvement with the community, and with advocates all over the country, and, indeed, internationally.

In this issue we introduce a very exciting development in health advocacy—one in which we have been integrally in-

MergerWatch

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cently, the EMTALA document* was passed on to the District Attorney of Connecticut for review.

An internship placement at MergerWatch is an excellent opportunity for a health advocate. I learned an enormous amount about the specifics of EMTALA and how Catholic hospital policies are administered; about policy research and capacity-building in advocacy; and about how a small nonprofit stays afloat—with healthy endowments and a lot of personality. Most important, I felt my work was important for CT advocates and the consumers they serve, which helped me to strive for excellence and accuracy.

*See "Voices" page of www.sl.c.edu/health_advocacy.

involved: formation of the Health Advocates Association (HAA), a professional association for health/patient advocates. The insert will introduce you to the retreat where advocates from academia, voluntary associations, provider organizations and the proverbial "kitchen table" debated whether such a diverse group of advocates could connect professionally. Could we—and *should* we—come together to support each other, to build the capacity of each and all, and to enable those who seek an advocate to find and assess services and the advocates who deliver them. We hope you will read the statement and be interested enough to respond.

The "outer wrapping" of this Bulletin is a snapshot glance at some particularly interesting new internship experiences



and new HAP programs. (You will find more information about the work of students, faculty and alum on our website: www.sl.c.edu/health_advocacy.) Our exciting next issue is a special issue on narrative and advocacy, edited by Pat Stanley, HA '05, and Sayantani DasGupta, a pediatrician and writer who teaches "Illness Narratives" in the Health Advocacy Program.

APPLIED RESEARCH ETHICS CERTIFICATE PROGRAM

*For Health Advocacy students and healthcare professionals
seeking career change or advancement*

Enhance your advocacy skills by enrolling in this program. As the research arena grows ever more complex, there is an increasing need for professionals who can skillfully address research-related issues in clinical settings, research organizations, oversight agencies, and disease-specific groups and local communities. You can begin the Certificate program in January or June. To learn more, visit www.sarahlawrence.edu/ARE.

PAATHWAYS: PARTNERS IN ADVOCACY FOR AGING TOWARDS HEALTH

A group of students from the Health Advocacy Program, together with Mary Tierney, HA '04, a geriatric care manager, and Director, Marsha Hurst, are piloting a new advocacy program for seniors. We are working with seniors at the Mount Vernon Armory, a senior center in our neighboring town, with the goal of developing a model of senior advocacy that can be widely applied in the County.

PAATHways is a program of the Westchester Alliance, co-sponsored by a Coalition of organizations and agencies:

- The Westchester Public/Private Partnership for Aging Services (PPP).
- The Westchester County Department of Health,
- The Health Advocacy graduate master's program of Sarah Lawrence College
- The Mount Vernon Office for the Aging and Office of Recreation.

PAATHways trains health advocacy students, working under supervision, to:

- Enhance the senior's knowledge about health, health care access, systems, and patients' rights.
- Empower seniors and encourage them to take a leadership role in their own health and healthcare decisions.
- Facilitate positive change in health outcomes through more informed care, improving the senior's quality of life.

PAATHways is a program that serves the needs of seniors:

- Navigating the health care system
- Empowering "voice" and communicating with doctors & other caregivers.
- Making difficult treatment decisions.
- Understanding and managing (chronic) disease.
- Dealing with end of life decisions.
- Understanding health related documents (health literacy).
- Accessing resources (being e-literate).
- Being safe at home.
- Being supported in choices about where and how to age.

Health Advocates Association

Shelter Rock Retreat on Health/Patient Advocacy

April 10-11, 2006

PREFACE

We came together from different places, with different hopes and fears, goals and uncertainties – united by our common commitment to ensure that those who place their trust in advocates, at a time of dire need, will receive competent, caring, skilled services from advocates who are supported by an organization worthy of national prominence and respect.

INTRODUCTION

A small group of Health Advocates came together April 10th and 11th, 2006, in Shelter Rock Long Island, to determine whether there is a need for a professional association of Health Advocates. Reservations, questions and possibilities were debated during the two day “retreat.”

BACKGROUND

There were at least two specific events that precipitated the Shelter Rock retreat. One was a “Patient Advocacy Summit II” organized by JoAnne Earp, Elizabeth French, and others in Chapel Hill, North Carolina, in March of 2005. At this meeting, issues of credentialing, professionalization of advocates, development of competencies for the field, and tensions between “lay” and “professional” advocates arose repeatedly. At the end of the two days in Chapel Hill, many left feeling a keen need to address these issues more thoroughly and more directly than had been possible at that Summit.

The second precipitating event was a meeting at the Genetic Alliance conference in Washington D.C. in July of 2005. Numerous members of the Genetic Alliance had requested a society or association of health advocates, to be both an umbrella organization, offering ‘lay advocates’ benefits and networking, as well as a resource connection for training opportunities. Sharon Terry called a 7 am forum, inviting any advocate to express her/his need for such an entity. An Internet listserv was created for further discussions, a survey of interested members was disseminated, and the results pointed to a real need for an association, separate from the capacity-building services and policy drafting offered by the Genetic Alliance.

GOALS OF THE SHELTER ROCK MEETING

Our primary goal at Shelter Rock was to explore and affirm the many differences between Health Advocates, while at the same time determining whether our common ground is solid enough to support a core profession. We set out first to see if we ourselves could come to know and trust one another, acknowledging with open eyes the silos and forms of marginalization that exist in the advocacy world while simultaneously looking for what we have in common.

A second set of goals – attended to later in the meeting, and summarized below — focused on addressing the many strategic issues which arose once we began to affirm the need for an Association of Health Advocates.

THE ADVOCACY LANDSCAPE

The group spent time in the early part of the retreat defining who is now doing health advocacy, and the various kinds of work such advocates do. We agreed that definitions are not standardized, and that terms currently in use – e.g., patient advocate vs. health advocate; consumer vs. patient vs. resident vs. client – are problematic and divisive. Advocates occupy a wide range of positions in the workforce (paid and volunteer) and advocacy may involve playing many roles. We affirmed the need

SIGNATORIES PRESENT AT SHELTER ROCK, APRIL 10-11, 2006

Donna Appell, Hermansky-Pudlak Syndrome Network, Project DOCC
 Sarah Davis, Center for Patient Partnerships, U of Wisconsin (Madison)
 JoAnne Earp, Dept. of Health Behavior, School of Public Health, U of
 North Carolina
 Elizabeth French, Dept of Health Behavior, School of Public Health, U of
 North Carolina
 Martha (Meg) Gaines, Center for Patient Partnerships, U of Wisconsin (Madison)

Rachel Grob, Sarah Lawrence College
 Janis Guernsey, Autism Speaks
 Maggie Hoffman, Project DOCC – Delivery of Chronic Care
 Marsha Hurst, Health Advocacy Program – Sarah Lawrence College
 Elda Railey, Advocacy Institute of Research Advocacy Network
 Laura Weil, Beth Israel Medical Center
 [Elizabeth Hamlin, Health Advocacy student; meeting recorder]

to distinguish between:

- individuals who are advocates, e.g., Julie Beckett, who advocated successfully for legislation to better serve the health needs of her daughter, Katie, and other families; or individual clinicians (doctors or nurses) who may go beyond being a health provider and act as an advocate on behalf of others;
- organizations that are advocacy organizations, e.g., Families USA, Gay Men's Health Crisis, Breast Cancer Action, Muscular Dystrophy Association;
- roles that are advocacy roles, e.g., subject advocate in a clinical trial, chair of a state legislative health committee, patient representative in hospital.

We agreed that central to all advocacy is functioning as a **change agent**, either by directly causing productive change for health/health care and/or by empowering others to do the same. Health advocacy includes direct service advocacy (working with or for individuals/families); legislative/policy advocacy; research advocacy; community-based advocacy (working with or for a geographically-defined group); population-based advocacy (working with or for a group defined on the basis of a shared health/illness experience or other characteristic); education advocacy.

Advocacy work can be done from a number of different settings/bases, including: grassroots advocacy networks or groups (the "kitchen table"); the not-for-profit sector; provider institutions (e.g., hospitals, nursing homes); community organizations or clinics; for profit corporations; labor unions; government agencies; legislative bodies.

There is a history of organization by advocates. In 1971, under the auspices of the American Hospital Association, the Society for Healthcare Consumer Advocacy¹ (SHCA) was founded as an *association* of mainly hospital-based patient advocates. SHCA remains a membership organization of the American Hospital Association rather than an independent professional association.

WHY AN ASSOCIATION OF HEALTH ADVOCATES, AND WHY NOW?

Would an association of Health Advocates be useful to advocates? Would it be useful to the public? Why are these questions arising now? Why have we all taken two long days to be here examining them? After extensive debate, it was agreed that such an organization would not only be useful, but that it is necessary, for the following reasons:

- It will help health advocates make our presence felt, and help us be leaders in defining shape/direction of a profession that is showing definite signs of coalescing.
- It will give us infrastructure to marshal the power of a

common voice, and a way to be heard by the media.

- If we build such an association now, it will ensure that the organization is "born and raised" by health advocates rather than by a more narrowly constituted group, as has been the case among hospital-based patient advocates, and threatens to happen in the corporate patient advocacy environment or among medical practitioners who hang out their advocacy "shingle,"
- It will help answer the questions, "Where do you go if you want to be a patient advocate," and "How do you become an advocate?"
- It will help people already in the field who ask, "Where is the professional voice of Health Advocacy?"
- It will better equip advocates to do their jobs in an ethical, competent way.
- It will protect the public by providing some guidelines about ethical conduct and professional standards.
- It could provide benefits such as health insurance, pension plans, group trips, and discounts.

It will not be easy to build an umbrella association flexible enough in its commitments, purposes, and influence to accommodate the diverse array of health advocates now working in the field, cohesive enough to create a meaningful professional identity and voice, and coherent enough to be held to useful standards by the public. The process of professionalizing includes losses as well as gains – including a possible loss of the creativity/flexibility which makes true advocacy effective and draws so many to the work, and the potential for increased cooptation. Fears that the Society will create insider/outsider status, excluding advocates without specific educational credentials, or those without personal life experience with illness, surfaced consistently throughout the discussions at Shelter Rock. A second issue returned to again and again was the importance of the association being truly *useful* to its members, and of taking care not to duplicate functions already fulfilled by others in the advocacy landscape (e.g., the direct provision of advocacy education/training, which is already available from multiple sources). The Shelter Rock group affirmed a commitment to attend to these and other sensitive issues in an on-going way as the first steps towards building a concrete membership association for individual health advocates are taken.

The working name for the proposed association is **Health Advocates Association**. It would be an organization

If you are interested in receiving updates as the Health Advocates Association develops, please email:

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We welcome your comments and suggestions, as well as your offers of more active participation in HAA.

¹Founded as the National Society of Patient Representatives

COMMON GROUND: WHAT 'PROFESSIONAL' HEALTH ADVOCATES SHARE

The Shelter Rock group agreed that an essential function of the retreat was to define principles, values, competencies/skills, professional ethics, and tools/strategies that we feel should be affirmed and embraced by all health advocates, regardless of position, role, or background.

Principles. All health advocates should

1. Promote equity and justice in health care
2. Promote health
3. Work on behalf of others
4. Maintain Hope

Values. Health Advocates should be guided by the responsibility and commitment to:

1. Respect the context, values and preferences of each person, group, and community we serve;
2. Be an agent of productive, positive change;
3. Idealism and to the "impossible dream";
4. Finding, using and sharing the best quality knowledge available;
5. Serving both the individual and the group;
6. Promote and protect patient rights;
7. Personal transparency about motives, limitations, and conflicts of interest great addition;
8. Multiple pathways for attaining Health Advocacy credentials.

Ethics. The meeting concluded that Health/Patient advocates should study the professional ethics of related professions and begin a dialogue that will result in the

development of professional ethics that could be a foundation of professional development for advocates. A task force is moving forward with this work. After a code of professional ethics is developed, membership in the Association would include a commitment to the ethical standards agreed on by the profession.

Competencies/skills. Health Advocates should possess the ability and capacity to:

1. Identify and support each person, group and community, taking into account and respecting their context, history, values and preferences;
2. Build capacity for others (patient, family, support network, organization, policy);
3. Ably, fairly, and honestly "represent" others;
4. Communicate effectively;
5. Facilitate access to support;
6. Know personal limits, including
 - a. What you don't know,
 - b. Limits of funding pressures, institutional ideology,
 - c. When you cannot competently represent;
7. Understand how the health care system works;
8. Recognize and disclose conflicts of interests.

comprised of individual health advocates, not of health advocacy organizations. The definitions we developed are summarized above.

PATHWAYS TO PROFESSIONALISM

The Shelter Rock group affirmed and reaffirmed that the purpose of the Association is to provide essential resources and support to everyone who wants to be an advocate. The Association is by no means designed to be exclusionary. Although the group agreed that credentialing is necessary in order to protect the public and create an articulated professional core for the health advocacy profession, we remained emphatic that *the path-*

The HAA is being formed to serve a membership of health advocates. Some of the benefits will be:

- A journal
- A website with information for advocates and consumers
- Health insurance and pension plans
- Opportunities for networking
- Mentoring new health advocates
- Seeing the commonalities among advocates
- Identify and promote workshops and educational opportunities in a range of venues

ways to eventual "credentialing" through the Association must be flexible and inclusive. Such pathways might include: direct experience (survivor, family member, etc.); formal education; career/professional experience; training (i.e., mastery of a body of knowledge); independent (or self-designed) study.

LOOKING TO THE FUTURE

Questions still open for debate include:

- What should be the organizational structure of the Association?
- What would be the criteria/processes for evaluating credentials of individual members?
- Should there be defined criteria for joining and maintaining membership?
- Should membership be self-determined, independent of competencies?
- Should members be required to meet certain standards or be working toward certain competency level?
- Should prospective members meet certain skill-based, experiential and/or educational standards?
- What kinds of benefits (e.g., health insurance) and services (e.g., vetting continuing education programs) should the Association plan to provide?

Comments about the Health Advocates Association. The Executive Summary was sent by each attendee to a few colleagues to get reactions. The comments below come from a wide range of advocates including those in the following type of roles and positions: capacity-building for community health organizations; patient education; independent health advocacy consulting, HIV/AIDS advocacy, counseling and educating; health advocacy education; state-based specific disease group policy advocacy; research advocacy; advocacy for caregivers; physicians involved in patient-centered care initiatives; physicians working as independent patient advocates; advocates for improved end-of-life care; reproductive rights advocates; advocates for those with disabilities; health/patient advocacy students.

Membership. Almost all respondents felt strongly that membership should be open and self-identified, i.e., dependent on your own identity as a patient or health advocate, not on an external validation or verification. Some felt that their right to be an advocate was integrally related to the right to free speech, and could therefore not be subject to validation or verification by others. The diversity of advocates should be valued and enhanced by the Association. For example, advocates who play the following very different types of roles could find the Association useful:

- Health advocate working within a larger advocacy organization, e.g., AARP or OWL for seniors, National Partnership for Women & Families
- Physician or nurse working as a clinician who self-identifies as a health advocate
 - Note: Groups of health care professionals, providers, workers or clinicians are not, simply by definition or because they believe advocacy is part of their job, included as advocates
- Research subject advocate or IRB coordinator
- Founding director of a small-non-profit organization to advocate for people with a particular disease or condition
- State coordinator of a disease specific advocacy network
- Disability rights advocate
- Attorney advocate in reproductive rights organization
- Legislator who heads the Health Committee of a state or municipal legislative body
- Health advocate who monitors a particular health issue, e.g., prescription drug safety or medical errors

Membership (as stated in the Executive Summary) is as an individual. It is not organizational. Thus membership is not dependent on current role or position as an advocate. The founder of a disease-specific not-for-profit who leaves to take a position as director of a community health research initiative or to run for local office can still self-identify as a patient/health advocate.

Membership would require a willingness to post certain information on the organizational website including information about advocacy experience, training and education and to accept ethical guidelines.

Ethical guidelines (additions). *Each member should “value the scientific basis underlying health care and corresponding laws and policies, and support research to provide scientific underpinnings for health care treatments (inclusive of alternative therapies)”*

Retreat attendees affirmed this value emphasizing that alternative, complementary or integrative therapies should not be excluded, nor should experimental treatments done within the oversight procedures of the scientific community.

There were concerns that political ideology and advocacy priorities could be divisive factors among advocates; but these concerns were counterbalanced by hope that there would also be common ground that increased over time in importance.

Respondents also emphasized the importance of agreement among advocates that the Association promote the value of increasing resources for prevention, treatment and research rather than being forced into competing within the advocacy community for scarce or limited resources.

Value was also placed on the commitment of advocates to getting accurate and timely information to the public.

Commitment to change was seen as a core ethical value. This could be interpreted as commitment to individual empowerment as well as commitment to change in the health care system itself, by, for example, creating a system easier to navigate for everyone.

Professionalization. The “voice” of the Association, would be effective in promoting advocacy itself and access to advocacy for the public.

Respondents emphasized the importance of providing information about advocacy and advocates to consumers, including both educational and clearinghouse functions.

Of concern to a number of respondents were the practical organizational questions, e.g., funding, leadership, staffing, sustainability.

For future consideration: Credentialing. Credentialing was thought by many respondents to be an important function of an Association, but also a divisive issue. Most felt that open membership to begin with would help create a solid professional association that could deal with issues of credentialing down the line. In other words, credentialing need not be a goal of the Association at its founding, and might work itself out as the Association progressed.

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