

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

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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.