

Letter from the Interim Director

By *Laura Weil*

We are presently in the midst of an extraordinary time for health advocacy. Our field seems to have come to the surface of everyone's awareness — a Google search for health advocacy now produces over 29 million hits. Universal health care is suddenly one of the top issues in a presidential election. Those of us who identify ourselves as health advocates are not as often asked "um... what is a health advocate exactly?" Rather, we often hear that "We really need health advocates. I wish I'd been able to find one when..." This change speaks to a substantive recognition of our role as it relates to improving the experiences of people encountering the health care system's deficits, a prevalent acceptance of the fact that U.S. health care is not necessarily the best, and that our wild expenditures are not producing superlative care. There is a growing sense that we might actually be able to change something this time around.

The Sarah Lawrence Health Advocacy Program also needs to explore change in order to ensure that we remain strong in this arena, build collaborative relationships with other players, and position ourselves to train and deploy advocates who have the skills and knowledge to be effective.

During this transitional period, we are extremely fortunate to have the insight and wisdom of an exceptional group of dedicated professionals in the advocacy world who have agreed to serve in an advisory capacity for strategic planning and repositioning to assure that our curriculum and focus remain pertinent and valuable in the changing terrain.

As an academic/professional health advocacy graduate program working to identify our strategic center, we continue to wrestle with the distinction between *patient* and *health* advocacy. It's clear that these are intersecting realms, rather than discrete ones. The

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Formation of the Health Advocacy Advisory Board

By *Meg Gaines*

The confluence of a new president at Sarah Lawrence and the leadership transition in the Health Advocacy Program has created a rich opportunity to step back and reflect on the program's past, while at the same time planning for its future. To that end, the college has convened an Advisory Board comprised of 16 diverse leaders in the health advocacy field. Members include those from academic settings, those representing advocacy organizations from within and outside health care, individual advocates and representatives of the alumnae and faculty.

Following the Board's inaugural meeting in September 2007, four subcommittees were convened to address issues related to curriculum and faculty affairs, strategic initiatives, recruitment

and retention, and the relationship of the program to the health advocacy discipline. Each subcommittee has worked diligently throughout the fall and winter. The second full meeting of the Board took place at Sarah Lawrence on February 1 and 2, 2008. The Board will issue a report to President Lawrence, Dean Watts and the Graduate Studies Committee in 2008.

When HAP was established at SLC 25 years ago, the goal was to ameliorate an increasingly complex health care system that was failing to meet the needs of patients and provide equitable access to either health or health care. In the intervening quarter century, these problems have grown more daunting. At the same time, the opportunities for and responsibilities of advocates have grown commensurately. As the founder and director of a "sister" health advocacy program at the University of Wisconsin, Madison, I am excited to chair this Board and be part of a vibrant process that reflects Sarah Lawrence's rich tradition of higher education's humane engagement of real world problems.

The Advisory Board welcomes and encourages participation from all who have an interest in the future of HAP. Meetings are open to observers. Comments, ideas and suggestions can be sent directly to me at mgaines@wisc.edu. Check the HAP website for a list of members and information about future meetings and activities of the Board.

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Letter from the Editor

By Barbara Robb

We've invited recent HAP graduates to describe their work in this issue of the Bulletin. I'm struck by how many of the graduates have found positions related to aging and senior health care issues. A current student in the program, Marleise Brosnan, has contributed an article about her internship, which also involves seniors. The Health Advocacy Resource Center is a health information center for seniors and their caregivers, established in partnership with the Westchester Library System and the Westchester Medicare Rights Center. Last year HAP was involved in another partnership, when students interacted with seniors in Mount Vernon in the PAATHWAYS (Partners in Advocacy for Aging Towards Health) program. These programs have brought our health advocacy training into the com-

munity, increasing public awareness of HAP and involving the College in collaborations with other Westchester organizations.

Mary Tierney knew that she wanted to pursue a career in geriatric care management even before she enrolled in HAP. Sandra Arellano was dedicated to her work on behalf of Hispanic/Latina breast cancer patients, and has continued to work in the same arena after graduation. Many of the other contributors, though, started their HAP studies with no specific job in mind. Most found their way to their current positions through their internships. Jane Nyce, Julie Buyon, Joyce Jacobson and Lois Steinberg all work at organizations where they did fieldwork. Barbara Winrich and Christine Dyer gained experience on Institutional Review Boards as interns, which led to their current work in clinical research programs.

What other paths have HAP graduates taken? Unfortunately, it's hard to tell. There is no up-to-date compilation of positions held by program graduates. Too many graduates have lost touch with the College and HAP. We could be a resource for one another, a source of information about advocacy issues, as well as internships and job openings. I'd like to invite HAP alumnae to become involved again, whether by sending comments and suggestions to Meg Gaines, Chair of the new Health Advocacy Advisory Board, attending one of the upcoming programs at Wrexham or sending current contact and employment information to Laura Weil at lweil@sarahlawrence.edu.

Barbara Robb graduated from the Health Advocacy Program in 2007.

Letter from the Interim Director

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recognition of the interplay informs the functioning of a Sarah Lawrence health advocate. Our Program's distinctive focus is that star at the center of the map, the icon that indicates "you are here," representing the patient lost in a confusing, unresponsive and fragmented health care landscape. Our essential mandate is the articulation of patients' collective and individual voices to service providers and policy makers, in order to transform their messages into concrete improvements in access, quality and system structure. The Health

Advocacy Program is exceptional in that we resist the outside-looking-in perspective of other academic and professional disciplines with which we share the advocacy arena. This is clearly our defining characteristic.

We haven't remained entirely static while waiting for the Advisory Board to formulate its broad-stroke recommendations. This fall we implemented a new advising system for all Health Advocacy students and built in a faculty role for Practicum support and oversight by creating a new course to lay preparatory groundwork and provide objective structure for fieldwork placements. The

new Intentional Communication course has been expanded to a full 14 weeks in recognition of the essential nature of effective and strategic communication skills in the professional advocacy arena. In the spring, we will welcome a new faculty member, Rebecca Johnson, who will teach a History of Health Care course. She will also be responsible for coordinating and mentoring a Health Advocacy Writing Group to support students' skills in written communication from an academic and professional perspective. Throughout this academic year, we have significantly increased faculty involvement in planning and collaborative leadership. I have been extremely fortunate to have had the generous support and exceptional wisdom of the Health Advocacy Program faculty community.

In this issue of the Health Advocacy Bulletin, *Notes from the Field*, you will find stories that exemplify our advocacy perspective. The issue is gratefully dedicated to all of our extraordinary graduates.

Notes From the Field

Building a "Do It Yourself" Retirement Community

By Jane Nyce

So far, I like the name "do it yourself" retirement community best. The concept is otherwise known as "virtual retirement" community and in the health care literature as "aging in place." The goal for the new non-profit Staying Put in New Canaan program is to provide the practical resources to allow seniors to live confidently and safely in their community as they age.

The "aging in place" concept has been around for a number of years in several different incarnations, but it got a national boost following the press attention given to Beacon Hill Village in Boston in 2006. I am aware of over 100 such programs in development around the country, with many opening, as we are, in 2008.

Staying Put in New Canaan, like Beacon Hill, will tackle many of the potential difficulties of staying in your own home and community as you age. The town of New Canaan has about 2500 people over age 65. This generally affluent community has excellent resources available to seniors, including a subsidized ride program, a senior center, numerous programs at the Y and library, and a renowned local health center for geriatric assessment, assisted living, rehabilitation and nursing home care. However, many residents still find themselves unaware of the many options for obtaining help or making social connections, or find themselves overwhelmed with the difficulty of getting around or keeping their homes well maintained and safe.

We will offer a one phone call link to transportation, technology support and home maintenance and health care services offered by local community resources, volunteers or professional service providers, as appropriate. Our volunteers might do errands, give rides to grocery shopping or the local senior center, visit those more isolated, house sit, provide computer support, or take seniors to their medical appointments. Professional service providers are vet-

ted for their reliability, quality of work, honesty and price value; most offer reduced rates for their services with our organization.

On the positive side, we are also addressing the isolation of seniors by offering social programs and cultural events or trips. Every month, we will have monthly get-togethers for our members. The events may be in town or within a couple of hours drive, such as a trip to the Stamford (CT) Symphony, Yale Art Museum, or a local dinner and a movie. Of course, we make sure there is transportation to any social program. Members receive the link to these services and programs through an annual membership of \$360 for a single person, \$480 for a couple or \$100 for those with significant financial limitations. Otherwise, we are funded through foundation grants and individual donors. We opened our doors to members on Jan. 2, 2008.

I started as Executive Director in October. The offer for this position stemmed directly from working with this start-up as my final internship last summer, at which point I was asked to apply and interviewed along with over forty other candidates for the job. In retrospect, this program is a perfect fit with my degree in Health Advocacy and my prior 25 years in business. It gives me the opportunity to use my project management experience to organize over 100 volunteers, contract with numerous service providers, create an operational resource center, and most importantly, reach out personally to the over 150 members as needed. I have responsibility for working with members of the board on the business plan, budget, communication pieces (brochures, quarterly newsletters, newspaper articles and website), and for creating links to local services and speaking to groups of potential members or other town organizations.

What do a typical couple of weeks bring? I have:

- worked with the Board on two grant proposals

- done an interview with a magazine focused on retirement options
- given a talk to a local group about our program
- worked on defining the quarterly newsletter
- met individually with several volunteers, members and service providers
- drove a member to get her arm x-rayed after a fall (that couldn't wait until January!)
- worked on the structure for our Access database
- presented a report to the Board
- worked with a committee on our kick-off party and winter events
- talked to two out-of-state relatives about what we can (and cannot) offer for their mothers.

Needless to say, the job is great if you like a lot of variety. I am looking forward to the opportunity to plan the future development of this program around the needs of the seniors and the town.

Thankfully all of my internships at SLC and some of my class projects somehow involved the theme of seniors. When I started at Sarah Lawrence, I had no expectation that I would work in community advocacy. The Health Advocacy program opened my eyes to the range of areas where we might tackle health issues and forced me outside my comfort range to try new arenas through my internships. By having a range of experiences in my internships, my community health project in my own town, and my involvement in the PAATHWAYS program with the Mount Vernon seniors, I became more confident that I would find work with seniors fulfilling (to say nothing of its being directly applicable to my own long-distance caretaking for my mother and stepfather). I feel well-equipped to make this a long-term sustainable program and true benefit for the town of New Canaan.

Jane Nyce graduated from the Health Advocacy Program in 2007.

www.slc.edu/health_advocacy

The HEALTH ADVOCACY BULLETIN is a publication of the Health Advocacy Program at Sarah Lawrence College, One Mead Way, Bronxville, NY 10708.

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Becoming an Entrepreneur in Geriatric Care Management

By Mary Tierney

Increasing numbers of people are living to advanced ages in the United States. Most older people prefer to remain in their homes as they age, but that may be possible only with the help of family and friends. In many cases, with or without family assistance, other supportive services may be needed. For those who can afford the fees, which are not covered by insurance, the services of a geriatric care manager (GCM) may fill the bill. Typically, the care manager will assess the client's needs, arrange services and monitor care on an ongoing basis. The care includes the hiring, training and monitoring of support staff.

While there are numerous large geriatric management companies doing business in the New York metropolitan area, I chose to go into business by myself. I like the independence of being able to pick and choose my clientele. I do use several colleagues as backup for those times when I am out of town.

With each new client, I like to begin my assessment in the home with particular emphasis on safety. Area rugs, slippery bathtubs, frayed electrical cords or other hazards can be disastrous to the health of the elderly. A fall which results in a broken hip or pelvis can set a senior on a downward spiral from which she never fully recovers. Simultaneously, I try to confirm that all legal issues, such as wills, DNRs, health care proxies and, whenever possible, end-of-life arrangements, are in order. I attempt to maximize the effectiveness and minimize the time spent on visits to the doctor by preparing a "visit to the physician" packet. The packet includes a list of current medications, contact information for all the client's physicians, health care proxy, DNR, HIPAA release forms, brief medical history, copies of insurance cards and, most importantly, a list of questions for the physician. I also ensure that a packet of these documents is readily available for use by emergency staff.

As with most businesses, I find that it is the staff who present the most challenging problems. Dueling family members can also create problems. If one is not careful and mindful of who the "real" client is, the senior can get lost in the mix.

Last week was fairly typical. In the course of the week I have:

- accompanied a client on a visit to his internist and nutritionist
- spent nine hours at the emergency department with a client
- visited the Martha Stewart Center for Living at Mount Sinai Hospital
- enrolled a client in a palliative care program
- conducted a team meeting for the five aides (from four different countries) who care for one of my clients
- handled payroll and negotiated a raise for aides
- resolved a conflict between siblings of a client
- met with hospice program workers for a client, and discussed death and dying with his family
- lodged an appeal for a client regarding denied Medicare benefits
- interviewed two prospective clients.

My journey to geriatric care management actually began with a Certificate in Gerontology from Marymount Manhattan College. One of the instructors in the program was a GCM and the description of the work she did interested me very much. The program required an internship, which brought me to the Medicare Rights Center, where I volunteered for two years. On my very last day there I met a wonderful Sarah Lawrence graduate who told me about the Health Advocacy Program. In a flash, I knew the next door had opened for me. Marsha Hurst was a wonderful resource for finding internships with a particular emphasis on seniors and aging. My first internship was at Jewish Home and Hospital (JHH) in New York, where I worked in a program sponsored by Medicare. Its sole purpose was to support seniors

with aging in place. The internship not only provided the hands-on work with seniors that I needed, but also gave me a window into medical jargon and hospital bureaucracy. The contacts that I made at JHH have served me well in my new career.

Constance Peterson helped me get over my fear of "blood and gore" by providing a mini-internship in the Emergency Department at New York Presbyterian Hospital. The New York Presbyterian experience was an absolutely necessary precursor for my next internship at Stanford University Medical Center, where I was privileged to have a diverse list of responsibilities. I was particularly interested in the subject of death and dying and was fortunate enough to be able to attend a three day seminar on the subject that was offered to the hospital staff. In addition, I spent a significant amount of time with a psychiatrist who counseled women in the breast cancer unit. Other duties included encouraging patients to complete advance directives and visiting and consoling the sick, the dying and their families.

My final internship was at New York's largest geriatric care management company. That practical, hands-on experience gave me the confirmation that I had chosen the right career path.

I have been asked if I could have started my business without attending the Health Advocacy Program. My response is a resounding "NO." Marsha's leadership and encouragement, the knowledge and confidence gleaned from teachers and colleagues, the connections and the networking have been invaluable. And more than 80 percent of my clients have come through referrals from people I met through the program. HAP is much more than classes and worksheets. Extracurricular events such as conferences and lectures solidified my foundation. HAP gave me the confidence to go out into the world and reinvent myself!

Mary Tierney graduated from the Health Advocacy Program in 2004.

Empowering Hispanic/Latina Women

By Sandra E. Arellano

The Comadre a Comadre program was founded in 2002, when a group of Hispanic/Latina breast cancer survivors in Albuquerque, New Mexico, declared a need for a bicultural/bilingual support group. Working with Elba Saavedra, Ph.D., they received funding in 2003 from the national Susan G. Komen Foundation to establish a group with Dr. Saavedra as Program Director. I have worked with the Comadre program since 2003. I was fortunate enough to be able to do two of my HAP internships with the Comadre a Comadre program and now work for the program full-time.

The Comadre a Comadre program is comprised of three main components: one-on-one peer support; patient education, information and referrals to cancer services and other community resources; and a bilingual breast cancer support group that meets twice a month. We are committed to empowering the lives of Hispanic/Latina women and their loved ones through advocacy, education, information, resources and support about breast health and breast cancer. The program is an educational initiative of the University of New Mexico's College of Education and is funded by the Central New Mexico Affiliate of Susan G. Komen for the Cure and the Santa Fe-based McCune Charitable Foundation.

Our initial efforts were focused on breast cancer, but we have recently expanded our mission and efforts to include the importance of breast health. We have encountered many women with breast cancer who did not know where to go to get a mammogram and who were unfamiliar with community resources that help pay for mammograms. As a result, these women were often diagnosed at a much later stage. In particular, we found that women do not know about the New Mexico Breast and Cervical Early Detection Program

(BCC), which provides free yearly "Well Woman" exams for eligible women. In response, we have developed a pilot project with a focus on breast health education, designed to educate women about early detection of breast cancer and to link them with resources for getting a mammogram. This pilot project has been in partnership with the Comadre a Comadre Program; the Breast Cancer Resource Center, an initiative of St. Joseph Community Health Foundation; the New Mexico Department of Health, Breast and Cervical Cancer Early Detection Program; First Choice Community Healthcare; and the Central New Mexico Affiliate of Susan G. Komen for the Cure.

As the Comadre program's Health Educator and Advocate, I have been spearheading an effort to develop partnerships in the community to help make the breast health classes a success. The "Well Woman" classes are offered in Spanish and English at different community centers around town. I have been coordinating these efforts and conducting the classes. They are conducted in a *platica* format, which is a very informal conversational style used to maximize participation in a non-threatening way. The one-hour class covers the importance of breast and cervical health and aims to develop an awareness of local resources. Participants watch a

culturally appropriate video on breast health and are offered help making an appointment for the Breast and Cervical Cancer Early Detection Program's "Well Woman Exam." We are especially interested in facilitating appointments for women who are experiencing any symptoms. We also administer pre- and post-class evaluations to monitor the participants' increase in knowledge. Thus far, the participation and feedback have been wonderful.

In addition to the "Well Woman" classes, I also conduct one-on-one Breast Cancer Education Sessions for women who have already been diagnosed with breast cancer. Families are also a part of these education sessions.

Attending the Health Advocacy Program made me become more proactive in my role as a health educator. Although I've always taken the initiative in helping patients navigate their way through the health care system, the Program made me aware of the key role that I play as a health advocate.

Sandra E. Arellano graduated from the Health Advocacy Program in 2007.

Faculty News

Stories of Illness and Healing: Women Write Their Bodies, edited by **Sayantani DasGupta**, MD, MPH, and **Marsha Hurst**, PhD, was published by the Kent State University Press.

New York City Politics: Governing Gotham, by **Bruce F. Berg**, PhD, was published by Rutgers University Press.

Peter S. Arno, PhD, has developed a doctoral program in health policy at the School of Public Health at New York Medical College and will become the Director of Doctoral Studies in the Department of Health Policy and Management.

Creating New Positions: Health Advocacy in Local Government

By Joyce Jacobson

When I entered the Health Advocacy Program in September 2005, I pictured myself becoming a patient representative in a hospital setting: a champion of the medically needy, a protector of patients and a crusader against insurance companies. Since my previous career had been in the medical field as a physician assistant, I was aware of deficiencies in patient care. For over 20 years, I had practiced neonatal medicine; I was ready to contribute to patient care in a new way.

While I was nervous about returning to school after a 25-year absence, the HAP provided much guidance, support and direction. Every class, paper and project added a new layer of knowledge. Each internship — patient representative, quality improvement and ethics — gave me direct and indirect patient advocacy skills. However, it was a first semester class, Community Health, which served as the catalyst to my current position as the Health Administrator of my home town in New Jersey.

The assignment for the class was to choose a population within a geographically bound community and investigate an aspect of health care. After choosing the senior population in Lyndhurst, N.J., I went into the community to ask seniors and medical providers for their opinions. One of those I interviewed was the Director of Lyndhurst's Health Department, who also serves as the town mayor. This interview led to my appointment as Chairperson of the newly created Lyndhurst Health Council. With the mayor appreciating the need for an advocate, I was hired as the township's first Health Administrator.

The Lyndhurst Health Department (LHD) provides services with the goal of protecting the public's health. Preventive and educational programs are offered. Emergency preparedness, childhood vaccinations, restaurant

inspections and communicable diseases are among the issues we have addressed. As health administrator, I advocate at both the community and individual levels and serve as a health resource for our residents.

While some of my time is spent performing administrative duties relating to personnel issues, budgeting and grant writing, I also review and write local health ordinances with the township attorney. In addition, I reach into the community to advocate for specific health issues. Addressing senior groups, updating the town's web page, and writing articles and letters for local newspapers are some of the outreach methods. By joining Bergen County's Task Force to Increase Access to Health Care, I have been able to collaborate with various agencies to facilitate the enrollment of children in New Jersey's health insurance program, NJ FamilyCare.

Although I enjoy advocacy at the community level, I feel a special sense of accomplishment when working with individuals. In one such instance, I learned of a child's genetic health issues and her need for serial back braces for scoliosis while enrolling her in NJ FamilyCare. The mother told me about the insurance company's denial of claims, even though the braces had been pre-approved. With my medical knowledge and advocacy skills, I was able to ask questions, call the insurance company and the brace facility, and appeal the case. The appeal was successful, the child's claims have been paid and

the brace facility has agreed to make the next brace at no cost.

My most recent project has been to promote the knowledge and use of advance directives in town. When I first started my position, I suggested an educational program about health care proxies. I was told that residents would never agree to it, as end-of-life issues were too personal to be shared with the health department. However, when I asked a senior group if anyone had a living will and briefly described health care proxies, there was great interest. Residents now approach me for assistance in completing their health care proxies.

While my first profession came from traditional medical training, the HAP allowed me to view the health field through a different paradigm. I learned the importance of knowing the issues, networking, developing skills, having confidence, being available and keeping an open mind. I continue to advance my health policy interests by participating in lobbying events in New Jersey and Washington, D.C. I recently began a CDC-sponsored fellowship, PHLIER (Public Health Leadership Initiative for Emergency Response), conducted by the University of Medicine and Dentistry of N.J. The HAP has led me in directions I never imagined. The field of health advocacy can be what each advocate makes of it.

Joyce Jacobson graduated from the Health Advocacy Program in 2007.

Upcoming Events

February 20, 2008 Lisa Van Brackle of the Literacy Assistance Center will discuss Health Literacy.

March 5, 2008 Amelia Chappelle of the Genetic Alliance will discuss Direct-to-Consumer Genetic Testing.

Both events will take place at noon at Sarah Lawrence College in the living room at 45 Wrexham, Bronxville, NY. HAP alumnae are invited to attend these presentations.

Training Seniors To Be "Trouble Makers"

By Lois Saxelby Steinberg

Like most of the students in my HAP class, I knew exactly why I wanted to be a health advocate. I also knew my goal was to train others to be health advocates for themselves and others. I realized early on that I was programmed by my mother to be a rescuer: to speak up in the face of injustice and to take care of people who, for one reason or another, could not speak up for themselves.

I speculated that many of the skills honed in my previous work and life experiences would be transferable to health advocacy. These experiences involved several years devoted to evaluating the effectiveness of federally-funded educational programs, with the goal of documenting how the funds were being spent and the effectiveness of the programs. At that time, there was little research to identify the "best practices" for teaching children from different environments how to read. I went back to school and got a Ph.D. with the goal of influencing educational decision-makers. I gave up that idea when I realized that most educational decisions are based on politics. I began to research the effectiveness of educational advocacy groups. My dissertation in 1978 was on "The Politics of Bilingual Education in New York City."

When I realized I needed to be more realistic about my economic future, I transferred my research skills to marketing and became a vice president of a small "boutique" marketing research firm. By the time I was 70 I knew I did not want to retire and that I wanted to transfer my skills to health advocacy. When I read the Sarah Lawrence brochure about the Health Advocacy Program, I knew this was it.

Why health advocacy? In applying to Sarah Lawrence, I answered this question by writing, "I see several parallels in what is happening in health care and the concerns that led me to become an education advocate. Specifically, the field is becoming more and more complex and bureaucratic,

decisions that have profound impact on people's lives are being made by centralized decision-makers and the average — even well-educated — person is frequently intimidated by the professionals. Thus I see people feeling powerless and sometimes disoriented at a time when they need to focus their energy on their health."

My motivation was reinforced by my experiences in helping Rhoda, an 81-year-old friend who had some serious health conditions and no family member to accompany her to doctor visits. She was almost deaf and asked me to go with her to listen to what the doctors told her and then explain it to her afterwards. She did not want others to know about her hearing loss. Most of the health care professionals treated her with little regard for her dignity as a human being. She was aware of this and it was the primary reason she did not want them to treat her. I observed this thoughtlessness on most of the occasions when I took her to a major New York City hospital which was reputed, at the time, to have the "best geriatric center in the City." At least two doctors said she had Alzheimer's disease or another form of dementia, but did not want to perform tests to make a diagnosis. They treated her like a child. I wrote about Rhoda's issues in my ethics papers, and we frequently discussed them in Alice Herb's ethics classes.

These experiences with Rhoda and her health care providers reminded me of the way educators often treat "problem" children: they often talk about them in their presence. Because the doctors had decided that Rhoda was incompetent, they often talked to me rather than to her, even when I asked them to speak to her. Most of these professionals did not know how to listen to patients.

One of my HAP internships was with the New York Public Interest Research Group (NYPIRG), researching the history of the Family Health Care Decision Act. I became involved in a study of the politics surrounding the legislation, which had been lan-

guishing in the New York State legislature for years. The internship was supervised by the director of NYPIRG's Albany office. Through him, I met the director of the Center for Medical Consumers, who suggested I work with Friends and Relatives of Institutionalized Aged (FRIA), which was part of a coalition working for passage of the Act. FRIA became my third HAP internship. I worked to coordinate a lobbying effort to get the Act passed, and became even more aware of the need for family members and friends to become involved in health care decisions.

At FRIA I met a staff person who went on to work at the Medicare Rights Center (MRC), where she recommended me to start a new program in Westchester County: Seniors Out Speaking on Medicare (SOS Medicare). That program was launched in the fall of 2001 when we trained volunteers age 60 and over to give Medicare Minute presentations on Medicare rights and benefits to seniors throughout the County, mostly at senior centers. The Medicare Minute is a short, concise announcement about a new or important aspect of Medicare.

SOS Medicare is now in its seventh year. I oversee a program with more than 50 volunteers. The number of senior centers visited on a once-a-month basis has grown from about 10 in 2001 to over 40 today. Programs on Medicare benefits are conducted on request at approximately 45 additional sites throughout the County. On average, our volunteers reach between 1500 and 1600 people each month.

When the Medicare Prescription Drug benefit, known as Part D, began in 2006, our volunteers conducted 120 hour-long educational seminars on the new drug plans, reaching over 7,000 people. They provided one-on-one counseling to another 3,000. They continue to provide such counseling today.

Based on reports from our volunteers, as well as focus groups we conducted in

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Finding My Niche: Patient Advocacy in Palliative Care

By Julie Buyon

Dr. Joseph Sacco was a guest speaker in my Models of Advocacy class. He had done some remarkable work with sickle cell patients at Bronx-Lebanon Hospital and struck me as a uniquely compassionate and patient-centered physician. I thought of him when it came time to start my HAP fieldwork. He had just started a palliative care program and was generous enough to allow me to create an advocate role within the program. I had not had a particularly strong interest in palliative care, but I did firmly believe in patient autonomy and I had an intuitive sense that autonomy was often compromised at the end of life. To my surprise, I discovered my calling working in direct patient care with these seriously ill people and their families.

My position as Palliative Medicine Patient Advocate was first supported by a one-year grant from the Fan Fox and Leslie R. Samuels Foundation, which generously supports many programs to improve the health care of New York City's elderly. My work during that first year convinced the hospital that patient advocacy in palliative care provided a unique benefit.

Early in my internship, Dr. Sacco pointed out that the medical system is the way it is because we can now fix people. The health care system evolved to reward the saving of lives, not to care for the chronically ill, because everyone used to die from disease much sooner. The system is designed for people who are sick and get better, not for people who get sick and stay sick.

Palliative care is not about saving lives – it is about healing those who get sick and stay sick or die. It supports seriously ill patients from the point of diagnosis throughout the course of their illnesses. It may be provided concurrent with other medical treatment, including curative treatment. It provides a sorely needed continuity of care for patients during their hospital

stays. More often than not, palliative care at Bronx Lebanon Hospital is end-of-life care.

A recent week encompassed nearly the full gamut of patient advocacy in Palliative Care at my hospital in the south Bronx. The spectrum ranged from advocacy for individual patients to advocacy on behalf of a class of patients, and included advocacy through education of health care professionals and advocacy for institutional change.

Tuesday morning began as it usually does with rounds with the Palliative Care Team. Then it was a dash across the street and a long wait for the elevator to join the Oncology department on all hospital rounds. As we moved through the Oncology ward, I updated the cancer specialists on the oncology patients Palliative Medicine was working with and listened intently to the cases that had not been referred to the PMCS.

A newly admitted patient had just been diagnosed with pancreatic cancer. Although chemotherapy will be offered to this patient, I suggested that someone from the PMCS establish a relationship with the patient *now*, so that we will be able to assist in managing the terrible pain that usually accompanies this disease, as well as the side effects of treatment. While it will likely be many months until a discussion about end-of-life care is appropriate for this patient, by then the PMCS will have gotten to know him and his family and, more importantly, established trust. The Oncology team said “No, don't see him yet.” But as we saw the remaining cancer patients in the hospital, Oncology said “Yes” about two other patients whose long-term prognoses were poor and asked the PMCS to discuss hospice with another two patients.

Later that afternoon, I faced 30 or so senior staff from the nursing department and jokingly asked if anyone in the room was over 21 years old. A few people raised their hands and two were selected to witness the signing of my Health Care Proxy form. The group was

able to see how easy it is to execute the form and we moved on to a discussion of health care proxies and advance directives. Cocked heads, raised eyebrows and furrowed brows made it clear to me that much of this was new information for the staff, even though the Health Care Proxy form and instructions on how to fill it out are pasted on the walls of every floor in the hospital and given to every patient. I passed out forms to everyone in the audience, along with wallet-sized advance directive cards. It was my hope that many of the attendees would fill out their own proxy forms, and would leave the presentation with an understanding of how easy it can be to discuss a health care proxy with patients.

Later in the week, I joined Dr. Sacco as we explained to a 32-year-old woman, her mother and her 15-year-old son that her newly diagnosed cervical cancer had spread to many other parts of her body. She was very, very ill – too ill to withstand the toxicity of chemotherapy. Our team promised to call Memorial Sloan Kettering on her behalf to see if they might have a treatment to offer her. However, he also told her that it is possible that this illness may take her life in the next few months. The patient was too distraught for much talk, but she agreed to sign a health care proxy. I provided the family with information about a variety of resources, including cancer support organizations, major cancer centers in New York City (so they could seek a second opinion) and strategies for talking to children about a parent's terminal diagnosis. Most importantly, we provided information about the patient's medical condition in a compassionate and comprehensible way, and reassurance that we will be with the family throughout their journey.

I also spent some time analyzing the results of an evaluative tool I designed

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Finding My Niche: Patient Advocacy in Palliative Care

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to assess the efficacy of pain management by the PMCS. I designed the study as my project for Mike Smith's Evaluation and Assessment class while I was a student in the Health Advocacy Program. The study tracked how quickly the palliative medical practitioners were able to provide pain relief. In order to identify obstacles to quick pain relief, it included information on types of pain, underlying illness, location of the patient in the hospital and a few other factors. It was my hope that the results of the study would lead to improvements in the team's ability to control patients' pain more quickly, and it has indeed led to a hospital-wide change in pain management policy.

While I was at my desk (which was rare, because members of the Palliative Care Team spend most of our time seeing patients in the hospital), I made several follow-up phone calls to patients who had been discharged. Incredibly, we have been following two of the patients for nearly a year. I would like to think that the support of

the PMCS has contributed to their longevity in the face of terminal illness.

I also made follow-up calls to advocate on behalf of all people in long-term care facilities. A nearby nursing home sends patients to our hospital, but refuses to allow us to enroll any of them in hospice because it is not in their financial interest to do so. Working with the Medicare Rights Center and the Long Term Care Coalition, I have been investigating the legality of this stance, as well as exploring whether any other advocacy organization is involved in the issue of nursing homes and patients' rights to hospice care.

At the radiation treatment outpatient facility, the Palliative Care nurse practitioner and I caught up with a patient with pancreatic cancer. He had missed two follow-up appointments with his oncologist, and I was concerned that the window of opportunity for effective treatment might pass while he was coming to terms with his diagnosis. We rescheduled his oncology appointment, coordinated pain medication prescriptions with his primary care physician and elicited a

promise that he would keep his next oncology appointment. I will call him both that day and the day before to encourage him to keep the appointment. Should palliative chemotherapy not be an option for him, hospice care can provide him with improved quality of life.

Towards the end of the week, I spent over two hours on the phone one evening with another newly diagnosed cancer patient who happens to be a friend of my sister. Although this patient is herself a medical doctor, her fears, confusion and feelings of being overwhelmed are the same as those of the patients I work with at Bronx Lebanon, many of whom are economically disadvantaged, poorly educated and socially marginalized. Illness is a great equalizer.

Julie Buyon graduated from the Health Advocacy Program in 2004.

Training Seniors To Be “Trouble Makers”

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different parts of the County, we learned that ageism and intimidation are frequently experienced by many older people. This situation is compounded by the fact that many do not understand what their doctor tells them and don't know what questions to ask. These findings provided the rationale for our newest initiative: a series of

interactive advocacy training workshops around topics such as Speak Up to Your Doctor and How to Be Safe in the Hospital. Information about Medicare is embedded in the presentations. When participants hear about what others have done to ensure they get quality care, they are emboldened to become more active in managing their own health care. We always advise

them to be accompanied by someone who can speak up, in case they can't.

You might say that we're training a lot of people to be “trouble makers.”

Lois Saxelby Steinberg graduated from the Health Advocacy Program in 2000.

Managing Clinical Research Programs

By Barbara Winrich and
Christine Dyer

We both work as clinical research program managers for Harvard-affiliated medical institutions in Boston, Massachusetts. Barbara works at Massachusetts General Hospital (MGH) in the Francis H. Burr Proton Therapy Center. Christine works at Brigham and Women's Hospital (BWH) for the Transplantation Research Center.

MGH and BWH are founding members of the non-profit organization Partners HealthCare (PHC), which is an integrated health system that also includes community hospitals, specialty hospitals, community health centers, a physician network, home health and long-term care services, and other health-related entities. PHC is one of the nation's leading biomedical research organizations and a principal teaching affiliate of Harvard Medical School. MGH and BWH are also members of the seven institution consortium that forms the Dana-Farber/Harvard Cancer Center, an NCI-designated Comprehensive Cancer Center.

Barbara's route into clinical research began with her role as an Institutional Review Board (IRB) member at Boston Medical Center (BMC), where she worked in the Office of Patient Advocacy. As a Patient Advocate IRB member, she gained familiarity with the federal and institutional regulations governing clinical research. Reviewing protocols and consents, and collaborating with fellow IRB members and physician-investigators to improve the administration of studies and the informed consent process solidified Barbara's interest in the clinical research field. From BMC, Barbara moved to MGH, first as a study coordinator in the Breast Cancer Research Program in the Gillette Center for Women's Cancers. This move was facilitated through Barbara's supervisor from one of her HAP internships, who is now the Research Nurse Supervisor with the Breast Program at MGH. After approximately a year and a half at

MGH, Barbara was recruited into her current position.

Like Barbara, experience working with an IRB played a significant role in the path Christine took into clinical research. As a HAP student, one of Christine's internships was with the still young IRB at Hackensack Medical Center. In this role, Christine undertook an advocacy-perspective review of all current protocol informed consents. She also developed a new Conflicts of Interest policy for physician-investigators. Through these projects, Christine became familiar with the advocacy and ethical issues in clinical research, and knew that this was a career avenue she wanted to pursue.

Shortly after graduation, Christine gave birth to a beautiful baby boy and was able to spend two years as a stay-at-home parent. Utilizing her health advocacy background when re-entering the workforce, she accepted a position as study coordinator in the Division of Thoracic Surgery at BWH, where she focused on lung cancer and mesothelioma research. During this time she became a cadre member of the Cancer and Leukemia Group B (CALGB) Committee on Advocacy, Research Communications and Ethics. She left BWH for a short time to work at a private for-profit site management organization (SMO) managing cardiac clinical trials throughout the U.S. She was ultimately recruited back to BWH to manage renal transplant trials for the Transplantation Research Center, which includes a multi-million dollar NIH-funded grant to improve the field of organ transplantation.

Neither of us would say that there is a typical day in the life of a clinical research program manager. Both of us work closely with physician-investigators on protocol and consent form development, IRB submissions, safety and toxicity reporting, and data management. We meet regularly with patients and their families to explain the clinical trials they may be eligible for, and to review study

logistics with enrolled patients. Barbara also teaches a class entitled "Treating Your Cancer through Clinical Trials" to MGH patients and their families. Most recently, Barbara has overseen the preparation and submission of a collaborative, multi-million dollar research funding proposal to the NIH to fund proton radiation research. Christine's current focus is an NIH-sponsored multi-center study exploring a new biological marker and its efficacy in detecting early transplant rejection. She works in close collaboration with the NIH project manager to boost enrollment to this important study. She also works with the Renal Vision Council, a group of transplant patients working to raise money and awareness to benefit research in issues relating to renal transplantation. Their upcoming inaugural year is on track to raise \$3 to 4 million for research at BWH.

There are many approaches to the health advocacy field, and both of us believe in consensus building and collaboration to achieve goals. Research management involves serving various interests, including study investigators and staff, sponsors, regulatory bodies, institutional logistics, and ultimately, patients and their families. The advocacy approach to research management involves keeping all of these perspectives in mind while working for the best solution. Progress in medicine requires that novel approaches be tested in clinical trials. The regulatory and protocol oversight we provide is essential to this process.

Barbara Winrich graduated from the Health Advocacy Program in 2001; Christine Dyer graduated from the Health Advocacy Program in 2002.

Helping Seniors Navigate the Health Care Maze

By Marleise Brosnan

The Health Advocacy Program, in partnership with the Westchester Library System (WLS) and the Westchester Medicare Rights Center (MRC), recently opened its first Health Advocacy Resource Center in Westchester County, located at the Grinton I. Will Library in Yonkers.

The Health Advocacy Resource Center, a library-based health information center, was established to help older adults and their caregivers navigate the confusing maze of health care information. It's the first program of its kind to integrate a counseling component within a public library setting.

Patrons of the Center have access to the vast array of WLS print and online health care resources, with guidance from trained volunteer counselors. The counselors, each of whom is equipped with a laptop computer and printer, assist older adults and their caregivers in finding up-to-date and reliable information related to health care, prescriptions, Medicare coverage and other health topics. The Internet is not a familiar or customary information source for most senior citizens. It is often difficult for them to navigate and even more cumbersome to hone in on the most reliable and unbiased information sources. The advocacy program aims to provide a link between the consumer health information available on the Internet and seniors who can benefit from this boundless resource.

The center is staffed by Medicare Rights Center volunteer counselors who are trained by MRC on the ins and outs of Medicare. They also receive training by WLS on Internet search techniques specific to consumer health information and the WLS health-related links on the WLS website. The HAP faculty provide expertise and assistance when volunteer counselors encounter questions that are not covered in their training. Volunteers include nurses, teachers,

social workers, corporate executives and other retired professionals.

The Center represents a new type of service for libraries and builds on the resources of this very unique collaboration between a public library, a national non-profit organization and a graduate education program. The partnership is supported by funding from the Westchester County Department of Senior Programs and Services. In short, the library provides the place, the non-profit provides the qualified volunteers, the college provides the expertise and program coordinator and the county provides the funds.

I serve as program coordinator and manage the Center volunteer and outreach efforts, guided by the expertise and support of Lois Steinberg, Westchester Program Director of the Medicare Rights Center. Lois is a graduate of the Health Advocacy Program and a 2006 Purpose Prize Fellow.

The Center opened in mid-November of 2007 and has assisted more than 30 patrons. Thus far, the predominant inquiries and discussion themes with seniors and caregivers revolve around Medicare. With the infusion of private health insurance alternatives into Medicare, it has become an extremely complicated benefit program to understand and utilize. Seniors are in a quandary over their interaction with Medicare and its "moving parts" A through D, the twelve geographically-based plan choices organized as plans "A through L" and the confusing terminology of plan alternatives such as Medigap plans vs. Supplemental plans vs. Medicare Advantage plans vs. HMO or PPO or Original Medicare. Cost considerations for coinsurance, copays, deductibles and monthly premiums, and selection of a drug plan from the 55 offered in Westchester County also create confusion. Other Medicare pitfalls seniors can fall victim to relate to watching out for monthly penalties for failure to

choose a Part D drug plan at age 65, separate annual enrollment dates for Medicare Advantage plans and Part D drug plans and establishing prior "credible coverage." Even though I am a former Head of Human Resources with 20 years of corporate employee benefit experience, I still have difficulty wrapping my head around the current Medicare choices and considerations required of our elder citizens.

Seniors and caregivers consistently and without exception ask the same question, "Why are they doing this to us?" They voice a great sense of frustration and mistrust in regard to their Medicare coverage and are concerned that their lack of knowledge and expertise with the current system may cause them to make coverage choices that will ultimately cost them more than they can afford or need to spend on their health needs or, more importantly, may fail to provide them with the right coverage when they need it. The Center volunteers work diligently to provide seniors with reliable, straightforward information and also act as a sounding board for those seniors who express their disappointment with the current health care system. They feel perplexed and dismayed that they have worked all their lives and paid into a system that is intentionally complicated and onerous to deal with.

It is an invigorating and gratifying experience for me, as program coordinator, to be involved in a project that provides practical, real time, impartial information and empowers seniors to make informed health care choices and decisions.

Marleise Brosnan is a graduate student in the Health Advocacy Program.