

HEALTH ADVOCACY BULLETIN

The Journal of the Health Advocacy Program at Sarah Lawrence College

VOLUME 16, NUMBER 1

SPRING 2009

Letter from the Director

By Laura Weil

It's with great pleasure and humility that I've agreed to continue my work on behalf of the Health Advocacy Program. It's an exciting and challenging time to be here. I'm indebted to the College, the faculty, alumnae/i, students and organizational partners in the field for their generous support of the Program – and for giving me an ongoing opportunity to contribute to the growth of our profession.

January's *U.S. News and World Report* cites Patient Advocate as a "cutting-edge career" for 2009. I've spent the past 20 years as a patient advocate — and just as long trying to explain what "health advocacy" means to polite but mystified people — so I find their prediction to be an astounding development. It's a clear indication that our health care system's catastrophic shortcomings have finally reached the tipping point in public awareness.

Any objective observer of America's dysfunctional health care system must hope that the new administration's agenda will try to make it more rational. Our system isn't meeting our emotional, financial or clinical needs. The United States spends more per capita for health care than any other developed country,

yet we consistently measure far below most of them in the health of our citizens. Measure after measure of clinical outcomes in the U.S. is poorer than in other developed countries. The Institute of Medicine's *To Err Is Human* and similar reports outline our system's frightening failure to protect us from being harmed by medical error. We need to achieve substantial changes to make the U.S. health care system compare positively with that of other nations. If we

"... our health care system's catastrophic shortcomings have finally reached the tipping point in public awareness."

don't, we'll continue to be shamed and harmed by crushingly disproportionate percentages of GDP spent on embarrassingly poor clinical outcomes.

But our failures by themselves aren't why *U.S. News* has identified Patient Advocacy as a growth industry. Sick and often frightened people need help

navigating our fragmented and discontinuous health care system. They need access to good and consistent primary care that keeps them out of emergency rooms. They need help fighting denials of care by our for-profit payer system. They need someone who can help them access information, identify clinical centers of excellence, and manage the complicated and often cryptic minutiae of medical bills and insurers' explanations of benefit. They need someone to talk to, someone knowledgeable who can be a consistently available contact and support as they plot an often frightening course through diagnosis, treatment and recovery.

Patient advocates step in to provide such support. Sadly, support rarely comes these days from family physicians. Their ability to spend time with patients is compromised by unrealistic insurance reimbursements and the resulting need to see more patients in less time in order to underwrite the high costs of practicing medicine. Add to that our increasing reliance on complex medical technology, clinical micro-specialization, and the transfer of patient care away from the primary care physician to unknown and often geographically remote specialists, and it's no wonder that *U.S. News* expects the demand for Patient Advocate services to surge.

On some level, I'm sure we'd all love to see our profession's "cutting-edge" designation disappear, provided it did so because we had a rational system able to meet the needs of people seeking medical care, to keep people healthy and able to be contributing members of society, and which didn't impoverish patients — sometimes even those who have health insurance — or squander our nation's coffers by spending for medical interventions that don't work while denying access to basic primary care.

Until these changes come to pass, *U.S. News* and I believe that demand for our services will keep growing.

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Letter from the Editor

By Barbara Robb

As Laura Weil writes in her Letter from the Interim Director, sick and frightened people need help navigating our fragmented health care system. Providing that help is exactly what many graduates of the Health Advocacy Program are doing. Catherine Marcial coordinates a program in New Jersey that offers free cancer screenings to the uninsured. Farrah Schwartz is a patient education specialist at an inner-

city hospital in Toronto. Karlin Mbah is a helpline counselor at a nonprofit organization that focuses on issues relating to aging and long-term care.

HAP graduates are also working on changing our health care policy. Karlin's job has a second dimension — she is a policy advocate working for long-term care reform. Liz Hamlin works as a legislative assistant to Richard Gottfried, the Chair of the Committee on Health in the New York State Assembly. Amelia Chappelle is at Genetic Alliance, an

organization that hopes to use genetics to transform health care. At both the personal and policy level, Health Advocacy graduates are working to improve health care.

Current students in the Program are also involved at both personal and policy levels. Valerie McDermott's paper illustrates the personal issues involved in health care, while Stephanie Krieg's description of her internship in Ethics at the Veterans Health Administration focuses on policy changes.

Faculty Profile: Mary Ann Baily



Mary Ann Baily

Mary Ann Baily will be teaching the Economics of Health course in the Health Advocacy Program starting in January 2009. She has a doctoral degree in economics from MIT and is currently a research scholar in ethics and health policy at The Hastings Center, a bioethics research institute in Garrison, New York. She has many years of experience teaching health economics to undergraduate and graduate students in economics, public policy and public health at Yale University (1973-79) and George Washington University (1983-99).

In addition to her work at the Hastings Center, her non-academic experience includes membership on an Institute of Medicine Committee on increasing rates of organ donation (2005-06) and service as the staff economist for a presidential commission on ethical problems in medicine and biomedical and behavioral research (1980-1983). Over the past twenty-five years, she has carried out research and consulting projects on genetic screening; health care

access, rationing and quality improvement; organ transplantation; end-of-life care; and the implications of HIV infection, organ transplantation and Alzheimer's Disease for health care financing.

She is convinced that a working knowledge of basic economic concepts is a valuable asset for health advocates. In the past, she has thoroughly enjoyed teaching economics to students preparing for careers in public health and public policy, especially students who have had little previous experience with economics. She believes that the Sarah Lawrence program in health advocacy is an exciting educational innovation, and she is looking forward to working with its students and faculty.

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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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Letter from the Dean of Graduate Studies

By Susan Guma

I am pleased to announce to readers of the Health Advocacy Bulletin that Laura Weil has been appointed Director of the Health Advocacy Program, effective March 2009. Below is the announcement made to the Sarah Lawrence community by President Karen Lawrence.

I am pleased to announce that Laura Weil (HAP '94) has been appointed as the Director of the Health Advocacy program. As the interim director since September 2007, Laura has demonstrated impressive leadership in guiding the Program through strategic initiatives over the past months. Her career prior to the directorship involved hospital advocacy in major medical centers in New York City and leadership in the Society for Healthcare Consumer Advocacy. She serves as a grants reviewer for the National Institute of Mental Health, and on the Institutional Review Board of Beth Israel Medical Center. Laura has been on the Sarah Lawrence faculty since 1999. She brings to the HAP a keen understanding of the health field and its challenges, and it is clear that her voice and that of the program will be heard in the national debate on health care issues.

In this time of fiscal crisis for the country, the efforts of the Health Advocacy program, its faculty and alumnae/i become even more critical to all of us. Laura will provide steady leadership for the challenges ahead with her expertise and passion for advocacy.

We wish her well on her appointment.

As the remarks by President Lawrence indicate, the Health Advocacy Program has been thriving under the leadership of Laura Weil and HAP's excellent and committed faculty. Together they have worked on strengthening the curriculum and on developing several important initiatives. True to the mission of the college, the Health Advocacy Program has focused on how to nurture the individual voices of its students and how to enhance the professional experiences which are so much a part of our education. Among the HAP's many new initiatives are the following:

- **Mentoring** by HAP faculty focused on academic advising and career advice.
- **Capstone project** is required of students entering the program in Fall 2008 and later. The capstone functions to integrate coursework and field experience in a substantial culminating project, demonstrate students' expertise in a chosen area of specialization, and connect students with specific professional opportunities.
- **Advocacy specialization** in a substantive area (e.g., child health; older adults; mental health) is required by the end of the first year. Subsequent research and fieldwork assignments — including capstone — are tailored to further develop specific expertise, enhancing ability of students to demonstrate a proven track record of achievement in the field.
- **Writing support** is given through the biweekly "HAP Writing Group" workshop led by a HAP faculty member, where students can obtain support with general writing issues or guidance with specific assignments.
- **Fieldwork coordination** is provided by a faculty member who works closely with students, meeting with them regularly to supervise progress in the practice component of the program. The Fieldwork Seminar is structured to support the development of a professional advocacy identity.
- **A Spanish language group** meets weekly and fosters facility with medical and health care terminology for students and alumnae/i with existing Spanish language skills.
- **Professional opportunities/Career development** are emphasized. Regular bi-weekly email health advocacy employment opportunities are provided to alumnae/i, faculty and current students. The goal is to provide alumnae/i with opportunities for employment and

career advancement while enabling current students to develop future career goals. Coming soon: a web-based, keyword-searchable database of current health advocacy employment opportunities.

• **The Health Advocacy Bulletin** now focuses on alumnae/i achievements and careers to highlight concrete examples of the broad opportunities that exist in the field.

The Program has had healthy recruitment and retention of students through the efforts of many people, including Emanuel Lomax, our Graduate Studies Director of Recruitment and Admissions. Supported in its work by the Health Advocacy Advisory Board's report to President Lawrence and Dean Watts (see Health Advocacy Bulletin, Winter 2008), the Program will continue to strengthen its role in the community at large and work in collaboration with our many partners.

Notes from the Field

Bridging the Information Gap

By Farrah Schwartz

As health advocates, it is important to ask ourselves whether we are effectively communicating with our clients. How does the language we use impact the clarity of our messages? In health care, medical terminology and jargon all too often get in the way of clarity. In many cases, our jobs as advocates center around bridging the information disconnect between providers, systems and patients. In my role as the Patient Education Specialist for an inner-city tertiary hospital in Toronto, I help the hospital and its staff understand and address the challenges inherent in health care communications.

St. Michael's Hospital is a tertiary care center with 535 inpatient beds, over 5000 staff and 25,000 day surgeries a year. I work in the department of Risk Management and Quality Improvement. The Patient Education Program was created as a response to a recommendation from Accreditation Canada (the Canadian rough equivalent to the Joint Commission). The recommendation centered around the need for improved patient education, and I was hired to lead the way in April 2006.

I am responsible for developing and implementing a corporate strategy for patient education at the hospital. The first job when I arrived was to identify a framework for patient education — how it rolls out across the hospital and who is accountable for what. This includes a Patient Education Committee that I chair, as well as ties in to the 8 clinical programs, professional practice and nursing. I also worked with the Committee to develop standards and an approval process for our patient education materials. I have worked with other patient education managers in the province to do research into what hospitals across the country are doing in patient education. We presented the results from our study at the American Academy of Family Physicians Practice Improvement Forum in December.

A large focus of my work is health literacy. Health literacy is defined as the degree to which a person has the capacity to get, process and understand basic health information and services needed to make appropriate health decisions. Barriers to health literacy include general literacy limitations, medical and technical language, the complexity of health information, cultural barriers and physical challenges associated with illness, such as fatigue and pain. At an inner-city hospital with many elder and immigrant patients, both health literacy and general literacy are challenges to care.

As is often the case in these positions, patient education is supported in principle but remains under-resourced. Recently, we engaged in a strategic planning process that included an all-day workshop with key hospital stakeholders and the development of a written plan. Stemming from that process, I am working to get approval for a Patient and Family Library, information management systems to share work being done across the hospital and increased human resources. In tight times, it is very hard to get increased resources.

“At an inner-city hospital... both health literacy and general literacy are challenges to care.”

Before I came to the hospital, I spent quite a bit of time trying to figure out where I fit into the system. After I graduated from the HAP in 2003, I returned home to Toronto and tried to find the answer to this question in a health care system that was very different than the one I studied in the U.S. Though we have hospital-based advocates, the model of patient rights is not as far along as it is in New York State. Private advocates and advocacy organizations are not as widespread, and often focus on fundraising rather than widespread advocacy.

After the HAP I went straight into a postgraduate internship with the Cancer Quality Council of Ontario at Cancer Care Ontario, where I continued after completing the internship. CCO is responsible for planning and oversight of all cancer services in the province. I spent two years at CCO in two different positions, but did not feel I had an impact on the patient experience. I was focusing instead on technical and clinical solutions to waiting times, clinical quality issues and provider-centred initiatives. It was at this point that I first came across patient education, through a growing initiative at the provincial level to promote cancer patient education.

After working at CCO, I took a job with the Ministry of Health and Long-Term Care, working with the primary care renewal team as a Policy Analyst. Again, despite my dedication to primary care and my strong belief that in the Canadian system, primary care is one of the key opportunities for advocacy, I felt very far removed from the patient experience. I struggled with questions about how to fit into a health care environment that does not have the same opportunity for advocacy as in the U.S.

When I came across the job here at St. Michael's Hospital, I knew it was a great fit. The job provides an opportunity to effect change at a hospital level in a meaningful way for patients. I enjoy many aspects of my job, including the opportunity to see attitudes change and understanding grow about the need to communicate clearly and in plain language with our patients. I have had the opportunity to use many management tools and develop and implement organizational strategy. Though it took me a while to find my place as a health advocate in the Canadian system, I feel that the HAP provided me with an important lens for approaching this role that contributes to my success in change management at the hospital.

Farrah Schwartz graduated from the Health Advocacy Program in 2003.

Advocating for Changes in Long-Term Care

By Karlin Mbah

Long-term care is not a topic most Americans consider in advance. Not many people want to have a conversation about where they will go and who will care for them when they are old and frail and may be experiencing cognitive difficulties. Yet as the Baby Boomers enter their retirement years, the topic of long-term care is receiving more and more attention. I have volunteered with older Americans in some capacity since the age of 3, but never imagined it would become my career until entering the Health Advocacy Program.

I came to Sarah Lawrence expecting to grow my knowledge as an established professional patient representative. But after three eye-opening internships, two in women's health policy and research and one in a government Area Agency on Aging, I realized I wanted to affect patient-centered changes to health care on a broader spectrum than just one clinic at a time. Yet Sarah Lawrence also inspired me to continue helping individuals make their voices heard in an increasingly challenging health care system. An unexpected layoff from my job in women's health, and a crisis in my own grandmother's health, spurred me to explore the new career aspirations I had gained through the HAP.

FRIA: the Voice and Resources for Eldercare with Dignity is a 30-year-old New York City nonprofit that works for long-term care reform on both micro and macro levels. There are two main components to the organization. The first is a helpline which takes an average of 2000 calls per year. Helpline counselors:

- guide friends and family members seeking to uphold residents' rights;
- provide information on keeping seniors as independent as possible, both in the community and in long-term care settings; and
- answer questions about Medicare, Medicaid, health care proxies, caregiver support and much more.

The second main component is influencing policy. FRIA promotes patient centered changes in rules and regulations at the individual nursing home level and strengthens the multifaceted long-term care system through legislative action at all levels of government. FRIA also provides education by hosting conferences, providing guest speakers for college courses and disseminating public alerts on changes in eldercare law.

“... when it comes to health, the personal IS political and the political IS personal.”

At FRIA I am both a helpline counselor and the Policy Advocate. As a helpline counselor, I typically speak with friends and family members of older Americans who are facing a crisis in their health. My job is to provide callers with several options that could be appropriate for their older relative's care, then guide the caller in navigation of, and self advocacy in, the long-term care system. For example, a granddaughter might call about her grandfather who appears overmedicated each time she visits him in the nursing home. The granddaughter believes her grandfather has stopped eating and experienced a dangerous fall due to the overmedication. This caller would be guided in nursing home regulations on chemical restraint, nutrition and maintaining residents at their highest possible level of functioning. She would also be given tips and options on how to conduct a constructive conversation with the nursing home on proper management of her grandfather's health needs.

As Policy Advocate, I have a much broader role, working for change in legislation at the city, state and federal level. First, I organize and support the leaders of 34 Family Councils in New

York City and Long Island. A Family Council is a group of friends and relatives of nursing home residents. Councils work to support each other as caregivers and to improve nursing home services and conditions. In my first role as Family Council Coordinator, I brought together family advocates and representatives of nursing home staff to begin collaborative work to improve staff training with the goal of higher quality resident care. Secondly, I educate both legislators and the public on policy changes. My work with legislators involves lobbying, giving testimony and organizing letter writing or call-in campaigns to shape elderlaw for the benefit of the individual. Recently, I spoke at the NYC Department for the Aging Annual Plan Hearing asking the City government to avoid direct service cuts to programs for the elderly in the midst of the budget crisis.

For the public, I post the Citizen's Action Page on the FRIA website. The page provides information on current legislation in long-term care and offers citizens a variety of ways to advocate for change, from speaking up at proposed rule-making hearings to marching on Albany with coalitions for the aging. Through this page and the helpline, I also find and groom individuals to become advocates for FRIA's goals and mission at all levels of government. I recently provided tools for concerned citizens to speak out against the proposed New York State rule for neurobehavioral step down units in nursing homes. The step down units were proposed to provide greater independence for people with cognitive behavioral difficulties resulting from traumatic brain injury. Many of these individuals no longer needed extensive medical and psychological care, but were not yet ready to return to the community. In reality, the units are so poorly defined that nursing homes could warehouse any person with cognitive behavioral problems, gain from this warehousing by billing Medicaid at a higher rate, reduce resident independence and not

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Providing Preventive Care to the Uninsured

By Catherine Marcial

Since 2002, I have occupied the position of Coordinator for the SAVE Women Program, or, officially, the SAVE Women and Men Program. The purpose of the program is to offer free cancer screenings to people who have no health insurance, and who, according to an arbitrary calculation, are too poor to afford these tests out of pocket. The program operates out of the University of Medicine and Dentistry of New Jersey (UMDNJ), in Newark, and receives funds from the National Breast and Cervical Cancer Detection Program (NBCCDP) and the State of New Jersey's Department of Health and Senior Services. We also have a substantial grant from the Komen fund, although we do not have direct control over how those funds are spent.

Services are available to undocumented immigrants (who make up a large proportion of participants), as well as to medically sidelined U.S. citizens. For most of its twelve-year history, the program has used a mammography van which allows people to be tested on their own home turf, so to speak. This makes the service accessible for those who want to be tested but do not want to navigate a hospital system. It also provides relief to the already overburdened Breast Imaging Center at UMDNJ.

I can safely say that our uninsured participants receive the same grade of testing as paying patients, and probably better follow-up for abnormal results. Since UMDNJ is the public hospital in New Jersey, we are able — or at least have been until now — to guarantee that anybody diagnosed with cancer as a result of screening tests provided through the SAVE Program will be followed and will receive a full course of the indicated treatment, despite inability to pay. If the participant is a U.S. citizen or legal resident, NBCCDP also offers guaranteed expedited enrollment in Medicaid for anyone diagnosed with breast or cervical cancer

The SAVE Women Program is a small-scale initiative to bring preventive care to a medically neglected population. As program coordinator, I must frequently advise people about how to address various medical issues not related to cancer, referring them to specialists or to a specific clinic, providing them with contact names and numbers, reassuring them about their fears, telling them how to access funds designated for the medically indigent. Since many of our participants have not seen a doctor in years, it can easily be imagined how many other health issues they may have on their minds when they come in for mammograms. It is as if this free program is a small gesture towards a national health program, where everyone could get medical care without fear of intolerable financial cost.

“Many calls come...from desperate women who know that something is wrong, but have nowhere else to turn.”

The people who use our services are those whose expectations are low enough so that they are glad to take advantage of whatever health care opportunity comes their way. Many other people who are eligible for the program do not come — they are the ones who feel cheated or betrayed by the social system, or who have too many problems that they know about to go looking for other problems that can only be detected by x-rays or a pathology lab. We do draw participants from the latter group, however, when they are told, or can feel, that they have a palpable lump in the breast. Many calls come to the office from desperate women who know that something is wrong, and have nowhere else to turn. We get these women in for examination as quickly as possible; unfortunately

sometimes a long time has gone by before they hear about our program and the disease has reached an advanced stage.

I first heard of the SAVE Women Program right after its establishment, because I wanted to have a mammogram but had no medical insurance. I went to the hospital for examination and testing, because the program did not yet have a van. I was favorably impressed by the doctor and nurse I saw and the service I received. Afterwards, I was surprised that so few people knew about the program. I did one of my Health Advocacy internships there, and then began a part-time job contacting program participants for follow-up testing and setting up appointments, helped by my knowledge of Spanish and Portuguese. Finally, due to personnel shifts, the coordinator position became available and I took over. Although I don't work under direct supervision, I do have to contend with two bosses: the hospital and the State, both of which are very demanding agencies. For the State I have to play a part that is not always comfortable for me. For both agencies I have to satisfy innumerable bureaucratic requirements. In the hospital I must promote the program among various entities that can be sometimes in conflict with each other or unaware of what the others are doing. In this respect, the hospital reminds me of a jellyfish, which is said to be not one animal, but many smaller animals that have combined as a survival mechanism. By that analogy, UMDNJ is a pretty dysfunctional jellyfish. It is hard to promote the cause of a health care program for the poor in a place where everybody is watching his own back. There was a time when the hospital was flush with charity care funds and welcomed uninsured patients from the community, but with the economic downturn, those days are gone. But I, and the rest of the staff here, soldier on, feeling that many women depend upon us.

Catherine Marcial graduated from the Health Advocacy Program in 2000.

Advocacy from a Genetics Perspective

By Amelia Chappelle

During my graduate career in the Health Advocacy Program at Sarah Lawrence, I saw each class, assignment and field placement from the perspective of a burgeoning genetic counselor. For three years I studied Human Genetics and Health Advocacy, earning master's degrees in both areas. The field components of these programs enabled me to experience the connections between the clinical and the broader systems levels of health and health care. I worked in the genetics department of the March of Dimes and in the genetics services sections of state health departments. The experiences I had in and out of the classroom were transformative and directed my postgraduate career.

When asked to write a paper on any organization for the Health Care Policy class, I chose to write about Genetic Alliance, a nonprofit genetics advocacy organization. Writing the paper sparked my interest, and I had the opportunity to learn more after I applied for and received a scholarship from Genetic Alliance to travel to Washington, D.C. and attend Genetics Day on the Hill. In 2006, the Genetic Information Nondiscrimination Act (GINA) had hope of passing, but continued to meet legislative resistance. Genetic Alliance organized a day for advocates from every aspect of the health care system (health care providers, disease-specific advocates, industry members, students, etc.) to visit the offices of policymakers to relay the importance of protecting genetic information.

This first taste of advocating on the Hill gave me a profound feeling of connectedness to an important cause. And this first interaction with Genetic Alliance left me wondering if the unique, energetic, forward-thinking organization might be a professional fit. Directly after graduation, I accepted the position of Assistant Director of Genetics Resources and Services with Genetic Alliance and made the move from New York City to Washington, D.C.

Since joining Genetic Alliance I have learned it is a place of perpetual motion, constant self-evaluation and creativity. Over a period of 22 years the organization has evolved from an information hotline for questions about rare genetic conditions to an umbrella organization for disease-specific advocacy groups to an organization that works with all the players in the genetics and health world. Genetic Alliance continues to expand and reinvent itself. Our current goal is to transform health through genetics. As we learn more about human genetics our understanding of health changes, and the way in which we advocate and support each other also adjusts. This constant fluctuation is mirrored in our organizational commitment to openness — our transparent, candid, intellectual interrogation of our processes, products and interactions with others. Openness helps us to learn from our missteps, seek unheard perspectives and identify successes as we improve the health of individuals, families and communities.

“Our current goal is to transform health through genetics.”

Openness has allowed us to bring together diverse stakeholders to create novel advocacy partnerships. We do this by holding Summits and Salons on timely topics in genetics and health, often convening those unlikely to sit at the table together in an open discussion of health systems in need of change and the implications of improving those systems. We travel to professional society meetings, regional genetics collaborative meetings and content-specific meetings (such as meetings on newborn screening or family health history) to exchange ideas and resources.

Genetic Alliance's network includes disease-specific advocacy organizations, universities, companies, govern-

ment agencies, policy organizations, health care providers, researchers and individuals. We offer technical assistance to organizations, build and sustain robust information systems and actively work toward public policies that promote the translation of basic research into therapies and treatments. In particular, Genetic Alliance identifies solutions to emerging problems and works to reduce obstacles to rapidly improving health technologies and services.

We use listservs, webinars and other tools to connect our contacts into a network with thousands of shared resources, creative tools and new programs. We promote open access to information to support the translation of research into services and individualized decision-making. In all we do, we integrate individual, family and community perspectives to improve health systems.

As you may imagine, all this work takes a concerted effort from the Board of Directors, staff, interns and outside partners. My daily work is a mixture of internal and external meetings, writing, project management, travel and many, many emails! I direct and coordinate our resources and services overall, while managing a five-year grant from the Centers for Disease Control and Prevention, the Access to Credible Genetics Resources Network project.

At Genetic Alliance, I enjoy the excitement of learning new things and the responsibility of applying prior knowledge. The Sarah Lawrence Health Advocacy Program fostered many valuable skills: critical thinking, self-direction and creative problem solving. We are at an exciting time, when the future shows much promise for greatly improving health systems. Every Health Advocacy Program graduate is prepared to make a mark on the health of individuals, irrespective of the specific route taken. See you in the field!

Amelia Chappelle graduated from the Health Advocacy and Human Genetics Programs in 2007.

Ethics in Health Care at the VA: Student Internship

By Stephanie Krieg

Last summer I had the chance to intern at the Veterans Health Administration in their National Center for Ethics in Health Care. The center has three offices, located in Washington, D.C., New York and Seattle. I was involved in the New York office, which focuses on ethics consultation. For ten weeks each summer they employ several interns and essentially give them a chance to be a part of their program. In retrospect, this opportunity expanded my understanding of how fundamental ethical issues are in health care every day. It is one thing to believe this is an important area, but quite another to witness its importance. I have been interested in medical ethics ever since I majored in philosophy as an undergraduate. Subsequently, I was looking forward to finally seeing how integral ethics is in the “real world,” as opposed to its role in more abstract discussions in the philosophy classroom.

This was a particularly exciting time to be in the ethics center because they had recently rolled out their new approach to ethics in health care. This new initiative, called IntegratedEthics, emphasizes the importance of incorporating ethical practices into the culture of the organization. This approach is designed to improve ethics quality by opening up the scope of ethics to more than just the ethics consultation service. In fact, one of the modules used in the rollout of this new initiative discusses ethical leadership, recognizing how influential the leaders of the organization can be in communicating the importance of ethics and in making it a priority.

Throughout my stint with the ethics center, my fellow intern and I were treated as a part of the office. We joined our department for their daily staff meeting and had the opportunity to discuss the different cases they were working on. Ultimately, our supervisors included us in many of their activ-

ities. If a consult came through, we were able to be a part of the discussion. We learned as much about the dynamics of this busy team as we did about the ethics consultation process. Everyone brought their own unique perspective to the table and it was important to hear those different viewpoints. These issues are not black and white, but often exist in the space somewhere in between the two. Discussing them and researching the variety of concerns that came through helped them to reach a well-formulated recommendation, which the facility would hopefully find helpful.

“I could really see how an understanding and a dedication to ethics came through in patient care.”

In addition to thinking through issues such as informed consent, decision-making capacity, the disclosure of adverse events and the like, this experience allowed me to really see the ethics consultation process in action. I was able to sit in on the weekly ethics consultation meetings at the VA. I also went along on patient visits and saw how the interdisciplinary team exchanged ideas to reach a recommendation on the specific case. As interns, we were lucky enough to be able to sit in on the monthly ethics consultation meetings at Bellevue and NYU, so we could observe how these ethics consultation committees functioned. It was helpful to get such a broad sense of different ethics committees in the hospital setting.

One of the highlights of this experience was shadowing my supervisor on his rounds in the ICU. This was where I could really see how an understanding and a dedication to ethics came through in patient care.

His communication with patients and their families helped to clarify the goals for the patients’ care, even though they were uncomfortable conversations to have. They were necessary so everyone was on the same page while the patients were still able to speak on their own behalf.

Given how central ethics is in health care, I am certain I will take the ideas explored in this internship with me into my future career. Moreover, the importance of this area is even more apparent to me now. Ethics is not just a topic for philosophical conversations; it is something that impacts real people, in at times heartbreaking and difficult situations. If the VA is able to improve the ethics quality at their facilities to better meet the needs of patients and staff alike, I think more facilities may use a similar model in the future. The VA is already an acknowledged leader in health care quality and I am looking forward to seeing how this new approach to ethics will impact the health care world.

Stephanie Krieg is a student in the Health Advocacy Program.

Student Paper: The Death of Self

By Valerie McDermott

In the last six months of my mother’s life, I always knew where I would find her in her house. She would be on her side of the bed, a long thin bump under many blankets. Her glasses would be lying beside her, atop the *New York Times* crossword puzzle. More often than not, the puzzle would be blank. The rhythm of the puzzles, the clever themes, would all but escape her now — the words taken in to the brain and then lost in the opiate fog. Gone were the days when she would rise at 7:00 am and quietly bring in the paper from the drive. Armed with coffee, cigarettes and her worn dictionary, the spine nearly broken in half, she would tackle the puzzle, unrelenting until it was done. Sometimes she would be stymied by the Sunday theme, and she would wait for me to arrive, to help her crack the code. Together we would pore over the puzzle, each with a pen and a cigarette; forcing each other to think harder and be more clever than we could ever be alone.

My mother was known for her crossword puzzle skills, and she enjoyed that notoriety. She was a smart woman, but not in a bookish way. She couldn’t quote Browning or Hemingway, and she didn’t care what the Dow did, but she could remember all of your teachers’ names, your friends’ names and their dolls’ names. If she saw you in the gro-

cery store, she always had a smile and a kind word and could make a conversation out of your outfit, the two items in your basket or the thing you mentioned the last time she saw you. It wasn’t that she liked to talk, in fact she hated the phone, but she liked people, and she was good with them. She was social in a sincere way. A chronic list maker, she reveled in completing the tasks of the day and crossing them off her list. My mother’s illness took away that smart, organized, “call Dee when you’re in the foxhole” identity. It took that away and left nothing in return. Unable to do any of the things that she used to do, hers became a life identified by four-hour increments, the chutes and ladders of pain management, at which time she would take massive amounts of pain pills and then slowly go into that numb, film-covered place. I often wondered what it was like there, in that foggy place, and I would sometimes take out my contact lenses and lie on the bed with her. Together then, in the shadows, trying to make sense of the world around us.

One day a particular friend of my mother’s stopped by — the one and only time. My mother was in her familiar place in bed, her eyes closed, and her friend peeked in the room. She wheeled around and in a loud voice said, “Oh my God, she looks terrible, it can’t be much longer, can it? You’ll call me?” I was horror struck. Did this woman think that

one of the side effects of pancreatic cancer was hearing loss? Did she honestly believe that my mother’s fabulous sense of style and care for her appearance had been eradicated, although the cancer had not? My mother moaned as if she felt another bit of her self torn away.

My mother lost her footing that day her friend came to visit. She recognized that her accomplishments and achievements, and the perspective that others held of her, were reduced to the sum total of someone dying. Oh, she knew she was still a mother, a wife, a sister, a niece, but the New York career woman, the femme fatale with the great legs, the crackerjack puzzle solver were a thing of the past. Her identity now was the last twenty-four hours and the next twenty-four. She was pigeonholed, boxed, labeled and dismissed.

Identity can be a tricky thing. My mother hated being recognized as a sufferer of something, based strictly on her appearance. And yet, she didn’t mind turning heads at a young age based on the same thing. The trouble with a terminal illness such as my mother had is that there is no way to overcome the disease, or to reclaim a bit of your former self. It is a constant erosion of identity until the death tide just washes it all away.

Valerie McDermott is a student in the Health Advocacy Program. This paper was written for Sayantani Das Gupta’s Illness Narratives class.

Advocating for Changes in Long-Term Care

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be held to additional oversight or safety measures for the new wards. More on this topic will be coming soon to FRIA’s Citizen’s Action Page at <http://www.fria.org/fria/about/support/action/>

FRIA provides me with the opportunity to facilitate positive changes in health care on both the personal and

political levels. It was Sarah Lawrence which brought to the fore my awareness that, when it comes to health, the personal IS political and the political IS personal. We will all be affected by aging in some way, be it individually or through our loved ones. We should not have to face the challenges of growing older through the experience of one crisis at a time. FRIA helps both the government and the individual

plan ahead for positive aging, to meet the range of needs within an ever increasing elderly population.

Karlin Mbah graduated from the Health Advocacy Program in 2007. In addition to her work at FRIA, Karlin also does freelance grant writing for the US-Africa Children’s Fellowship. She is a board member and Clinic Liaison for the New York Abortion Access Fund on a volunteer basis.

Holiday Party

The Health Advocacy Program hosted a holiday party at Wrexham in December 2008. Graduates of the Program were invited, as well as current students and faculty. Joan Marks, who started the Health Advocacy Program in 1980 and was director of the program until 1998, was a special guest.



HAP alumnae and students with Rachel Grob, HAP faculty and Associate Dean



Joan Marks with HAP students



Julie Buyon and Yvonne Bokhour, HAP alumnae

Upcoming Meetings and Conferences

Narrative Medicine Rounds, College of Physicians & Surgeons of Columbia University

Narrative Medicine Rounds are lectures or readings presented by scholars, clinicians or writers engaged in work at the interface between narrative and health care. Rounds are free and open to the public. They are held on the first Wednesday of each month from 5:00 to 7:00 pm and are followed by a reception. Rounds are held at the Faculty Club, 446 P&S Building, 630 West 168th Street (between Broadway and Fort Washington Avenue), New York. For more information see www.narrative-medicine.org.

April 1, 2009

Julie Salamon will read from *Hospital: Man, Woman, Birth, Death, Infinity, Plus Red Tape, Bad Behavior, Money, God and Diversity on Steroids*.

May 6, 2009

Priscilla Wald will read from *Contagious: Cultures, Carriers and the Outbreak Narrative*.

June 3, 2009

Oliver Sacks will read from *Musicophilia: Tales of Music and the Brain*.

Changing Perspectives on Healthy Aging, The New York Academy of Medicine

The NYAM's Section on the History of Medicine and Public Health presents talks examining some of the profound ways in which basic expectations about aging and the aged have shifted in the last century. The talks are free and are open to the public. There is a reception from 5:30 to 6:00 pm, followed by the lecture from 6:00 to 7:00 pm. Talks are held at the New York Academy of Medicine, 1216 Fifth Avenue at 103rd Street, New York. For more information and registration see www.nyam.org/histmed.

April 6, 2009

Elizabeth Siegel Watkins will speak on "The Estrogen Elixir: Women, Hormone Replacement, and the Predicament of Aging."

May 7, 2009

Charles Rosenberg will speak on "Who Owns Old Age?"

Faculty Seminar on Narrative Genetics, The Institute for Social and Economic Research and Policy (ISERP), Columbia University

Narrative genetics is a new and interdisciplinary way to understand genetics in our lives, our culture and our politics. The seminars, like all ISERP seminars, are free and open to the public. The seminars are held from 5:30 to 7:30 pm in Conference Room 801 of the International Affairs Building, West 118th Street and Amsterdam Avenue, New York. For more information see: www.iserp.columbia.edu/workshops/genetics.html.

April 2, 2009

Alice Wexler will speak on "Narratives of Inheritance: Comparing Huntington's Narratives Across Cultures, Continents and Centuries."

May 7, 2009

Priscilla Walk will speak on "Clones, Chimeras, and Other Creatures of the Biotech Revolution: Towards a Genomic Mythology."

Intensive Bioethics Course, Kennedy Institute of Ethics

An intensive course in bioethics, Bioethics: Beyond the Sound Bite, will be offered at Georgetown University's Kennedy Institute of Ethics. For more information, see kennedyinstitute.georgetown.edu.

June 1-5, 2009

Save the Date

Friday June 19, 2009
Professional Development Seminar

"Program Development: From Idea to Implementation"

This interactive workshop, designed for the entire Health Advocacy community, will build skills and provide tools for implementing new programs and re-conceptualizing existing ones.