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HEALTH ADVOCACY BULLETIN

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The Journal of the Health Advocacy Program at Sarah Lawrence College

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Letter from the Director

By Vicki Breitbart

The Economy Is Bad for Our Health

The economic crisis dominated the domestic news the week I started as the as the new Director of the Health Advocacy Program (HAP). The unprecedented power struggle in Congress about how to deal with the debt crisis and then the downgrade of the U.S. credit rating were major headlines. The economic crisis has been going on for some time. As I write this today, we still find 13.9 million people out of work, and many more who are hungry and living in poverty, with no solutions in sight. Even those working in low-paying jobs are finding it hard to survive. Over 10 million people who are working are living in poverty.[1] A recent *New York Times* front page article reported that "another 2.6 million people slipped into poverty in the United States," making the number of Americans living below the official poverty line the highest since the government started collecting this data.[2] More children are being affected; in Westchester, the number of children living in poverty climbed from over 19,000 in 2006 to almost 28,000 in 2009.[3] At present, 22 percent of children in the United States are living in poverty—more than one in five—and 18 percent of families are "food insecure."[4]

> *"We are witnessing the devastating impact [of the economic crisis] on both access to services and health outcomes."*

In the HAP orientation we showed *Unnatural Causes*, a film made several years ago by California Newsreel, which demonstrates the impact of income inequities on health disparities. As compared with high income individuals, low income Americans are more likely to report that they have been diagnosed with chronic conditions, particularly depression, high blood pressure and diabetes. Recent information indicates that this situation has worsened; the gap between rich and poor continues to grow. In the last few decades, the income of the top .01 percent of Americans has increased fivefold, while the income of most other groups has basically remained the same or decreased. All of this is affecting the health and well-being of Americans.

As health advocates, we are witnessing the devastating impact of the economic crisis on both access to services and health outcomes. Even with insurance, people are unable to get the most basic care for acute and chronic conditions.[5] A recent report from the Robert Woods Johnson Foundation shows that employers are shifting the burden to employees by increasing premiums. Workers are experiencing reductions in coverage and increased out-of-pocket expenses as employers try to control benefit costs. Surveys of those still employed show workers are deferring care and experiencing adverse effects on their physical and emotional health; 27 percent reported they chose not to receive treatment because of the co-pays and 20 percent have skipped taking medications or are not taking them at the prescribed dosage.

At the same time, the number covered by employer-based insurance has continued to decline and the move to a more part-time work force means that more workers are likely not to be offered any health coverage. The number of uninsured is now up to almost 50 million. The lack of insurance affects people's ability to pay for health care and other necessities that affect health and health outcomes. There is an increasing trend for people not to receive needed medical care; they are foregoing elective surgeries and/or preventive screenings and deferring or cancelling health visits because of cost.[6] While many women have reported that they want to delay pregnancy due to economic hardship, they find it difficult to pay for contraceptives.[7]

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[1] Aaron, K. and Perri, L. Working but still poor. Sept. 13, 2011. www.americawhatwentwrong.org

[2] Soaring poverty casts spotlight on "lost decade." *The New York Times*, Sept. 13, 2011.

[3] *Westchester Children's Association Newsletter*, Fall 2011.

[4] Szabo, L. 1 in 5 U.S. children living in poverty, study reveals. *USA Today*, June 8, 2010.

[5] Darling, H. The recession's toll on employee's health: Results of a new national business group on health survey. Presentation at the National Press Club, May 27, 2009.

[6] Robert Wood Johnson Foundation. Issues in brief: Impact of the economy on health care. August 2009.

[7] Guttmacher Institute. Women of reproductive age hit hard by the recession. *News in Context*, Sept. 17, 2010.

Letter from the Editor

By Barbara Robb

Our Point of View article in this issue concerns the health effects of hydraulic fracturing, a process widely known as fracking. It's a method of using pressurized fluid to create fractures in rock, so as to release substances that can be extracted. The author, Polly Howells, is Chair of the Board of Bioneers, an environmental and social justice nonprofit organization. The Bioneers can best be described in words from their website: "Just as the web of life is intricately interconnected, so too are all environmental and social issues. We take a 'solve-the-whole-problem' approach that is holistic, systemic and multidisciplinary." Those words can also be applied to our field of health advocacy.

The Reports from the Field in this issue exemplify the multidisciplinary nature of health advocacy. Mary Morrissey reports on her fieldwork at an HIV/AIDS project in Tanzania, where she studied accountability and transparency concerning overseas aid. Emily Hickey reports on her fieldwork at the Waikiki Health Center in Honolulu, where she helped provide services to frail and elderly individuals as well as to homeless and runaway youth. Linda Koebner describes the establishment of a new program to use therapy dogs in palliative care at Montefiore Medical Center. Liz Givens writes about her advocacy work with youth at Families on the Move in New York City, work that is at the intersection of public health, mental health and education.

HAP faculty involvement is similarly multidisciplinary. Laura Weil describes her role as patients' rights advocate for the Nuclear Regulatory Commission's Advisory Committee on the Medical Uses of Isotopes. Rachel Grob's new book, Testing Baby, examines the sociological consequences of newborn screening programs.

Once again, we're introducing a new feature in the *Bulletin*. In response to reader requests, we've added a new section with student and alumni updates. If you have a new job, degree, certification or volunteer position, please let us know about it. Send the information to Gloria Escobar-Chaparro at gescobar@sarahlawrence.edu. If you're interested in writing an article about your work or a Point of View article about a topical issue, please contact me at brobb@sarahlawrence.edu.

www.slc.edu/health_advocacy

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Alumnae/i News

Shawna Irish, HAP '07, is Alumnae/i Relations Correspondent for the Health Advocacy Program. Please send her news of your work, personal achievements and milestones to be edited and submitted to the Sarah Lawrence Magazine. Shawna can be reached at shawna.irish@gmail.com.

In This Issue

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REPORTS FROM THE FIELD

Advocacy in Tanzania

By Mary Morrissey

My internship this past summer was with the Faraja center—an HIV/AIDS project in the town of Singida, Tanzania, East Africa. The center, which was established in 2002 by a faith-based organization called the Medical Missionaries of Mary (MMM), takes its name from the Swahili word for compassion. I had previously worked in Tanzania from 1987 to 1989 on a voluntary basis as a hospital administrator. Fate—and some networking—conspired to offer me an opportunity to return to a place and a people that I love.

> *"Accountability and transparency are important components of overseas aid."*

Tanzania relies heavily on overseas aid. Does this aid make a difference in the lives of ordinary people? Finding the answer to this question was one of the goals of my internship in Tanzania. I was also seeking evidence of accountability and transparency concerning aid donated from overseas.

I arrived at Kilimanjaro Airport on June 8, 2011. Sister Nuala Horgan, who would be my supervisor for the next ten weeks, was waiting for me. It had been 22 years since we had seen each other! The dedication and commitment of the MMMs is inspiring. Each day four nuns from this congregation—Catherine, Marian, Mbuotidem and Nuala—demonstrate that they are advocates par excellence in many ways as they provide testing and support for HIV/AIDS clients in a non-judgmental environment, with the help of a competent and compassionate Tanzanian staff. Reducing the stigma of HIV/AIDS is a major focus at Faraja. Employing staff who are living with the disease, like Shabani Jumanne, is one way of addressing that issue.

Shabani, a 46-year-old Tanzanian native, lost his first wife and his five-year-old son Juma to AIDS. During his short life, Juma was shunned by his peers–even children are aware of the stigma of AIDS. Shabani tested positive for AIDS in 2003 but could not afford anti-retroviral (ARV) drugs—they were only available to those with foreign currency to buy them. In 2005, free ARVs were made available through government hospitals in Tanzania. The protocol for treatment was a CD4 level of 200 or above. CD4 cells are the main target of HIV, with the number of CD4 cells decreasing as HIV progresses. With a CD4 of 13, Shabani was not eligible for ARVs, but the local HIV/AIDS coordinator approved his treatment. Shabani was sent home to die. With an indomitable will to live and a devoted mother to care for him, Shabani survived and in 2006 began to work at the Faraja center. He is an inspirational, gentle, serene presence—gracious, kind and filled with a joie de vivre that sometimes comes after a long struggle with illness and adversity.

Mary Morrissey and Shabani Jumanne at the Faraja Center, August 2011

> *"Overseas aid is a short-term solution, not a substitute for empowering local communities to participate in shaping their own future."*

Accountability and transparency are important components of overseas aid. Equally important are effective in-country distribution structures to allow aid to be distributed quickly and efficiently to where it's needed. The Faraja center depends on overseas funding. The local organization, which distributes overseas aid, is disorganized and puts a lot of pressure on the staff at Faraja—pressure that has forced the staff to focus on money and has left them worrying about when, or if, the promised funding will materialize.

Each country has different challenges; identifying these challenges is the key to finding a suitable solution. Donors must always be cognizant of the fact that overseas aid is a short-term solution, not a substitute for empowering local communities to participate in shaping their own future. This internship has made me sure that my career lies in advocating for social justice in developing countries and confirmed my belief that appropriate use of donor aid is an integral part of that advocacy.

Mary Morrissey is a student in the Health Advocacy Program.

Direct Client Contact in Hawai'i

By Emily Hickey

As a student in the Health Advocacy Program, I am required to complete a minimum of three internships. I want to use the internships to explore a variety of settings and work with a wide age range. My first internship was in research-based advocacy, which was a good experience, but I wanted my next placement to be one that would allow patient contact. I also wanted something outside of New York to get out of my comfort zone and to see if I could apply my newly acquired skills in the real world. So, during the summer of 2011, I interned at a nonprofit called the Waikiki Health Center in Honolulu, Hawai'i.

> *"Working at a small non-profit...allowed me to see concepts like harm reduction and patient-centered care in action."*

Originally known as the Waikiki Drug Clinic, the Waikiki Health Center was created in 1967 as a way to address excessive drug use by local youth. Their many programs include a temporary living placement called Next Step, the PATH (Perinatal Addiction Treatment of Hawai'i) Clinic, Care-A-Van and traditional Hawaiian healing.

The Waikiki Friendly Neighbors (FN) Program was created in 1986 and continues to assist the local frail and elderly population by pairing them with volunteers who provide companionship, light cleaning and help getting to the store or doctors' appointments. One of my responsibilities as an intern was to be a volunteer for Friendly Neighbors. I took on four clients, whom I saw once a week for a minimum of one hour each. The activities during these visits differed, depending on the needs of the particular client. For example, one client was wheelchair bound, had had a stroke, and had cerebral palsy. She needed someone to help her clean and do her laundry while also interacting with her and engaging her in conversation. The Friendly Neighbors are a key service for her because they allow her to live independently rather than in the nursing home that she adamantly does not want. Another client, however, just wanted company. She had Alzheimer's disease and therefore needed reminders about her medications and help retracing her steps. What was most important to her, though, was having someone to talk to. In addition to visiting clients, I did intakes, an interview and evaluation process for potential volunteers and new clients.

The Youth Outreach (YO) Center began serving homeless and runaway youth in 1989. The center has afternoon "drop-in" hours and an occasional educational group in the evening, featuring guest speakers. The guests choose topics that they think could be helpful to this population, whether it be sexually transmitted disease or anger management; other guests might conduct an art class. During drop-in hours, YO provides free services such as GED classes, a clinic that can act as a primary care center, canned foods and hot lunches, clothing, washing machines, hot showers and toiletries, as well as help getting food stamps, obtaining identification, building resumes and evaluations for prescription medications. The Center provides access to the Internet, a small basketball court and a weights room. My part in all of this varied on a day-to-day basis. I would start out helping with paperwork, organization and assisting the other staff member with current client projects. Then everyone would pitch in to prepare for drop-in, which could mean anything from cleaning to cooking to doing laundry. When drop-in started, I took down the names of everyone who came through the door, which could be anywhere from fifteen to fifty people in a day. I also had the opportunity to participate in the outreach team. The team consists of two or three people who go into downtown Waikiki at night with a backpack full of snacks, condoms, toiletries and cards with the YO address. They usually target YO-aged youth (up to the age of 21) and working girls (prostitutes) in hopes of attracting new clients and keeping them safe, healthy and possibly off the streets in the future.

> *"I want to use the internships to explore a variety of settings and work with a wide age range."*

Working at a small non-profit with direct contact with the population I was serving allowed me to see concepts like harm reduction and patient-centered care in action. I hope to continue to work with, and for, those values in the future. I hadn't considered working with teens before, but I learned a great deal about how and why they came to YO and would be interested in working with them again. I had volunteered for work with the homeless population several times before, but had never considered it as a career option. This internship allowed me to see what a career in this area entails and what it takes to run a non-profit. I am very grateful for the opportunity to work at the Waikiki Health Center and indebted to their hard-working, passionate staff for their help and support.

Emily Hickey is a student in the Health Advocacy Program.

Therapy Dogs in Palliative Care

By Linda Koebner

Animal lovers know the emotional, physical and social benefits companion animals provide, but these qualities are difficult to research scientifically. Since the 1980s there have been increased attempts to document their health benefits, especially to the young, the old and the disabled. Organizations like the Delta Society work to enhance the understanding of the human-animal bond, and even the National Institutes of Health has begun to study the positive effect of animals in health care. Among the benefits demonstrated to date are improved cardiovascular health, stress reduction, decreased loneliness and depression, and the ability of the animal to facilitate social interactions, as they do with Alzheimer patients; the dogs have also been found to be helpful for autistic children.

Yes, there are people who just don't care for dogs, cats, horses or rabbits. Some are afraid, have allergies or just have never had the experience of an animal's unconditional acceptance. And, although I am sure there are people who love insects, most animal-assisted activities or therapy involve mammals, including horses and monkeys, but most commonly, dogs.

People often confuse assistance and therapy dogs. An assistance dog is a dog trained to help a person with a disability in daily life. There are numerous types of assistance dogs:

- **guide dog** – trained to assist the blind or visually impaired;
- **service dog** – trained to assist disabled people by retrieving objects that are out of their reach and helping with tasks of daily living (pulling wheelchairs, opening and closing doors, turning light switches off and on, etc.); and
- **hearing dog or signal dog** – trained to assist the deaf or hard of hearing.

> *"It won't be long before patients in palliative care... will have canine visitors."*

Other assistance dogs, such as bloodhounds or cadaver dogs, are able to use their acute sense of smell to find people, living or dead.

A therapy dog is a dog trained to provide affection and comfort to people in hospitals, retirement homes, nursing homes, mental institutions or schools, as well as in stressful situations such as disaster areas. Institutions usually have rigorous requirements for therapy dogs. They may invite certain dogs to visit and prohibit entry to others.

Linda Koebner with her dog, Spirit

Recently I was able to see the creation of a therapy dog program at Montefiore Medical Center. I was most fortunate to have my first internship with Leslie Bank, Director of Customer Service at the hospital. One of numerous things we agreed on was the importance of animal-assisted activities in the hospital setting. Leslie had recently been granted permission to set up a therapy dog program for the palliative care unit. We created a committee of physicians, nurses and administrators to implement a plan customized for Montefiore. The head nurse of the unit named the program PET (Pet Enrichment Therapy). We set about drafting a policy that would take into account the needs of numerous departments, staff and patients. We looked at programs in other hospitals as models, but customized the program for Montefiore. The committee took into account the safety of patients, dogs and personnel, as well as legal and logistical issues. Through continuous review and feedback we explored everything from minute to major issues and concerns—from how often the dog's paws should be cleaned to who would decide which patients would receive visits. The policy was reviewed by specialists, administrators and staff. And now, it won't be long before patients in palliative care, if they wish, will have canine visitors. The dogs won't bring flowers, but I guarantee they will bring comfort.

I hope my dog Spirit will be one of the first dogs to visit. He came to me as a badly abused stray when I lived in Louisiana. From the beginning of our relationship I saw what a great therapy dog he would be. Outgoing and gentle, he LOVES to be touched, and, it was pointed out to me, is wheelchair height. I was trained through Jansen Hospice; Spirit went through evaluation and training with Therapy Dogs, Inc. We now have the immense pleasure of going to nursing homes and hospice. As soon as we walk in the door, patients ask "How old is he?" "What's his name?" "I had a dog" "Can I pet him?" He often elicits a quiet smile and bright eyes when he puts his head on patients' laps and they pet him.

I came to the Health Advocacy Program after decades of professional work advocating for non-human animals. Now I want to do more to advocate for the health needs of humans, and part of that work is to bring species together.

Linda Koebner is a student in the Health Advocacy Program.

Public Health/Mental Health Campaign for Schools

By Liz Givens

When I chose my Capstone Project at the Academy of Hospitality and Tourism (AOHT) at Erasmus High School, my main objective was simply to find something that interested me, and that wasn't related to mental health, which was my career before entering Sarah Lawrence. Bringing health advocacy to secondary education seemed a natural fit: improve educational outcomes, reduce health disparities and empower youth to be advocates regarding their own health needs. Traditionally, youth voice is under-represented in education, much as it is under-represented in matters of mental health care. As you learn in virtually every class in Health Advocacy, there are challenges inherent with the voice of minors in terms of legal consent, comprehension, cognitive ability, personal narrative, parental conflict and so on. As it turns out, the voice of youth is an ongoing hot topic across the child service delivery systems in New York.

Since leaving Sarah Lawrence, I once again find myself drawn to mental health. I have taken a job as the Special Projects Coordinator for Families on the Move of New York City, a nonprofit, family run, grass roots mental health organization dedicated to providing support, education and advocacy for families and caregivers of children and youth who are experiencing or at risk of experiencing emotional, behavioral or mental health challenges. Many of the advocates within the organization are youth who have gone through one or all of the systems--mental health, criminal justice, etc.—in New York. Their voice is vital.

> *"Youth voice is under-represented in education, much as it is under-represented in matters of mental health care."*

I have found encouraging youth ownership, voice and self-advocacy to be as much of a challenge in education as it is in any of the other bureaucratic systems. Community-based participatory research (CBPR) requires those with power to offer it and those without to accept it. Representation of youth voice within social services, while considered a best practice nationally, is an ongoing issue. It requires more than just gathering youth together for "representation." The dialogue should be meaningful, youth driven and produce results. I recently attended a Citywide Oversight Committee Meeting, or as we at the HAP like to call it, a meeting of gatekeepers, where representatives from the various offices within New York gathered to discuss issues impacting the delivery of children's services systemwide. Not surprisingly, there was only one youth present to represent youth voice, and only one member of the Department of Education, even though many of the issues raised involved health issues and education. This was an observation made during my Capstone: schools function as independent, isolated entities; however, the students within them have issues that travel across systems. Tremendous progress has been made by New York not only in recognizing the value of youth and family voice, but in steps taken to engage them. This behemoth, multi-layered bureaucracy will not change easily. The Department of Education and their involvement is just one small piece of a huge puzzle. The challenge facing New York in terms of mental health is to decide whether or not to keep working at fitting the pieces of these systems together, or to start with something new. The catch phrase is now cross systems of care--making them fit, and work, together. As a health advocate, I will always look to the persons receiving the services for the answers. While this is understood as necessary and important by the Office of Mental Health, youth voice is considered an adjunct to traditional services. CBPR is not currently discussed in this area of health, and not in the way that health advocates understand it.

> *"I envision a public health approach to mental health, an approach that is loosely being discussed with the New York Department of Health and Mental Hygiene, but still in its infancy."*

My vision is to find a way to bring education to the table at Families on the Move, so that I continue, albeit differently, with the project I began at AOHT. I envision a public health approach to mental health, an approach that is loosely being discussed with the New York Department of Health and Mental Hygiene, but still in its infancy. I firmly believe that a public health/mental health campaign in schools, from kindergarten on, that focuses on identification, awareness and stigma reduction can stimulate social change within a few generations. If we were to educate about mental health the way we educate about washing our hands or covering our mouths when we cough, system change could happen quickly. What is most encouraging to me is the way in which things come together. I chose AOHT because I wanted something different and new, and yet, as we learn in the program, everything is really interconnected. Health advocates become skilled at seeing this, perhaps more so than those in other disciplines, which is why it is so important to have us at the table. Families on the Move works with interns, and I would be happy to work with anyone interested in children's mental health.

Liz Givens is a 2011 graduate of the Health Advocacy Program.

POINT OF VIEW

The Health Dangers of Fracking

By Polly Howells

Hydraulic fracturing, commonly known as hydrofracking or fracking, is a controversial method of extracting "natural" gas from a layer of shale embedded up to 10,000 feet below the surface of the earth. The Marcellus Shale, one of the largest shale formations in the U.S., estimated to contain between 168 and 516 trillion cubic feet of methane, sits under much of New York State. Until now, fracking has been banned in the state, thanks to the mobilization of several environmental groups. However, a new environmental impact statement has recently been released by the state's Department of Environmental Conservation (DEC), and the public has until early December 2011 to let Governor Cuomo know our feelings about this method of gas extraction. If he mandates the drilling, as he is expected to do, the industry's long-term plan is for 77,000 wells to be drilled in upstate New York, at a density of eight wells per square mile.

> *"Until now, fracking has been banned in the state, thanks to the mobilization of several environmental groups."*

The quotation marks around the word "natural" in the paragraph above are intended to question the industry's contention that gas heat is superior, "clean" energy. It is cleaner burning than coal or oil, but getting it out of the ground is a very dirty business. The fracking process involves pumping millions of gallons of water, sand and toxic chemicals thousands of feet underground vertically, and then horizontally through the shale layer, to release tiny pockets of gas. Chemicals in the water cause the infused fluid to become viscous; the sand suspended in this mixture holds the fissures in the rock open so methane can be released. Fracking is exempt from a key provision of the Energy Policy Act of 2005, so the exact chemicals used in the process can be held as a trade secret. Despite this provision, researchers have been able to identify certain chemicals in the fracking fluid, which has been known to seep accidentally into groundwater. One of the ingredients, which creates serious health consequences at very low doses, is 2-butoxyethanol, a known endocrine disruptor, a substance that changes the way hormones move through our bodies. Endocrine disruptors have been connected to infertility, ADHD, autism, diabetes, thyroid disorders and adrenal tumors. Complicating the situation, fracking chemicals are injected so deeply underground that at temperatures of 120 to 140 degrees new chemical compounds are created. A common byproduct is a class of chemicals known as trihalomethanes, which have been definitively linked to bladder and colon cancers.[1]

> *"In their efforts to wring the last drops of fossil fuels from the earth…the gas and oil industries are jeopardizing the health and well-being of us all."*

In addition to polluting groundwater, hydrofracking affects air quality. Theo Colborn, president of the Endocrine Disruption Exchange (www.endocrinedisruption.com) and the researcher who has done the most extensive work on chemical pollutants resulting from hydrofracking, said at a recent gathering, "Fugitive methane and volatile organic chemicals may be released directly into the air around a well site. In addition to methane, these chemicals may contain the 'BTEX' complex (benzene, toluene, ethylbenzene, and xylene), hydrogen sulfide, diesel exhaust and nitrous oxides." She pointed out that when you combine diesel exhaust with nitrous oxides under a sunny sky you create ozone. Ozone at ground level is a pollutant that affects our respiratory system. "Ozone can burn holes in the alveoli of the lungs. Exposure to ground-level ozone contributes to asthma in children and adults as well as chronic obstructive pulmonary disease."[2]

The airborne contaminants resulting from the hydrofracking process do not only emerge from the wellheads themselves. Each time a well is fracked, approximately 1,000 truck trips bring to the site the two million plus gallons of water that are injected into it. This level of trucking produces diesel fumes, which, along with the particulate matter kicked up on the road and the chemical contaminants emerging from the pumping process (also powered by diesel fuel), create a toxic smog that can travel as far as 200 miles. Systems ecologist Susan Steingraber reports, "In adults, these pollutants are various[ly] linked to bladder, lung, and breast cancer, stroke, diabetes, and premature death. In children, they are linked to premature birth, asthma, cognitive deficits, and stunted lung development." She adds, shockingly, "In the gas-producing areas of Utah and Wyoming, formerly pristine air now contains more ozone than downtown Los Angeles."[3]

Another unintended consequence of hydrofracking is the release of radioactivity that has been held in the shale rock for 350 to 400 million years. Some radioactive material is a carcinogen

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[1] Smith-Heavenrich, S. The unhealthy consequences of Marcellus drilling. *Broader View Weekly*, March 4, 2010.

[2] Smith-Heavenrich, S. Theo Colborn addresses air, water issues related to gas drilling. *Broader View Weekly*, Feb. 20, 2009.

[3] Steingraber, S. The potential health impacts of hydraulic fracturing. Testimony before the New York State Assembly Standing Committees on Environmental Conservation and Health, May 26, 2011.

Two People, Three Hands, Four Eyes…One Voice

By Julie Buyon

On October 18th the Health Advocacy Program was one of five sponsors of a program celebrating voice and collaboration. The intersection of these organizations brought nearly a hundred people together to celebrate a collaboration of individuals—in particular, three graduates of the Health Advocacy Program—and organizations that assisted the late Neil Selinger in finding his voice and making it heard.

The primacy of patient voice is foremost in the MAC Angels Foundation, which supports patients with amyotrophic lateral sclerosis (ALS)—better known as Lou Gehrig’s Disease—and their families in a multitude of ways, ranging from individual support to collaborating with other organizations to bring programs such as this to the community. The same can be said of another sponsor, the Westchester End of Life Coalition, which strives to ensure that all Westchester residents have access to the information and care that supports them at the end of life. The Coalition was co-founded by former HAP Director Marsha Hurst. Patient voice is also central to Columbia University’s Program in Narrative Medicine, also a sponsor, which uses literature to promote greater humanism and humanity in medical practice and assist those dealing with illness gain new perspectives and meaning about that experience. Of course, the Writing Program at Sarah Lawrence is all about helping individuals find and refine their voices. Attentiveness to the patient’s voice is at the heart of the Health Advocacy Program.


Julie Buyon (at lectern), Dana Gage, Rima Grad, Steve Lewis, Heidi Weiss

Neil Selinger retired from his law practice in his fifties and pursued his dream of being a writer by enrolling at the Writing Institute at Sarah Lawrence. Just as he was beginning this new career, he was diagnosed with ALS and progressively lost his speaking voice and his ability to move. In spite of this, his first book was published earlier this year. Selinger enrolled in Steve Lewis’s Creative Nonfiction workshop in 2008 and over the next two and a half years wrote most of his first published memoir, *A Sloan Product.* After he was no longer able to attend class because of his illness, Lewis and several of Selinger’s fellow writing students formed the Bella Villa writers’ salon and brought the class to him. Selinger relied upon computer-assisted technology and the commitment of Dr. Dana Gage to craft his words into an inspiring and thought-provoking series of essays.

Advocacy can take many forms. Selinger’s health advocate and social worker, Heidi Weiss (HAP 2008), coordinates the Pathways to Care Program at Westchester Jewish Community Services, supporting individuals and families facing debilitating and life-threatening illnesses. Weiss had taken Sayantani Das Gupta’s Illness Narratives HAP course, and recognized the potential of that approach to assist Selinger. She reached out to a fellow HAP alum, Patricia Stanley (HAP 2005), who had joined the faculty of the Narrative Medicine Program at Columbia University. Stanley approached one of her students, Dr. Dana Gage, about working with Selinger. Gage, who has been a practicing physician for 30 years, and a writer for even longer, spent time with Selinger and his family while he completed his essays—his illness narratives—about living with ALS. She served as his scribe, writing coach, editor and collaborator.

Gage spoke about her work with Neil Selinger, and how it transformed both of them. She was joined in reading several of his illness narratives by SLC Writing Institute faculty member Steve Lewis, Selinger’s social worker Heidi Weiss and Selinger’s widow Rima Grad, a nationally known print artist. The essays spoke to the remarkable adaptability people facing devastating illness often find, the shifting priorities, the joy found in unexpected places and the transformation of self. “As my muscles weakened, my writing became stronger,” Selinger wrote. “As I slowly lost my speech, I gained my voice. As I diminished, I grew. As I lost so much, I finally started to find myself.”

Following the reading, Gage was interviewed by author Jamie Talan, who spent 25 years at *Newsday* covering “all things brain.” She is now an assistant professor of science education at Hofstra University and has just launched a literary journal for their School of Medicine. Talan said that she had never known such courage as when she sat opposite ALS patients who had lost their voices to this disease. But there they were, using their eyes to run a computer that helped tell their story. Writers, Talan has always said, have a duty to listen and report. And that is what Dana Gage has done so beautifully.

Julie Buyon is a 2005 graduate of the Health Advocacy Program. She is Patient Services Director for the MAC Angels Foundation, Vice President of the Westchester End of Life Coalition and serves as an advisor to the Center for Aging in Place.

FACULTY NEWS

Patients’ Rights Advocate for the Nuclear Regulatory Commission’s Advisory Committee on the Medical Uses of Isotopes

By Laura Weil

The Nuclear Regulatory Commission (NRC) is the federal agency tasked with regulating the use of nuclear byproduct material. It’s not just power plants—the NRC is also responsible for the use of radioactive material for medical purposes in cancer treatment and diagnostic imaging. How this material is stored, accounted for, used by licensed medical providers, the attendant patient safety and public health issues the material poses—all of this is subject to oversight by the NRC.

One might ask why the NRC feels a need to employ a patient advocate. In the process of regulating medical uses of nuclear material, NRC staff are advised by a group of professionals in the field: health physicists, nuclear medicine physicians, radiation oncologists, nuclear pharmacists, nuclear cardiologists, radiation safety officers…a list of people with technical expertise, but perhaps biased with an interest in making the process of practicing medicine with radiopharmaceuticals easier and more efficient for the practitioners. In its wisdom (or, if one were to be more cynical, perhaps it’s more about something self-protective), the NRC recognized that it needed someone with an unadulterated patients’ perspective on the books to provide a counterbalance to the provider point of view.

I’ve always relished this “insider” advocacy role, acting as the provocateur in what is usually a well-established medical machine whose operating priorities can allow it to lose sight of the end user—the patient. While the scope of the work is still evolving, here’s an example of what I’ve been involved in. In my first outreach as the newly appointed Patients’ Rights Advocate for the NRC, I attended the annual Thyroid Cancer Survivors Association annual conference (www.ThyCa.org), learning about the concerns of people who have undergone radioactive Iodine 131 treatment. The conference attendees expressed substantial and legitimate worries about the trend towards offering this treatment only on an outpatient basis (insurance generally won’t pay for inpatient stays) and the difficulty of minimizing gamma radiation exposure to others in the immediate post-treatment period. Of particular concern is the need for highly radioactive outpatients to travel on public transportation or stay in hotels immediately after treatment, exposing unknowing fellow passengers, hotel guests and hotel staff to potentially dangerous radiation levels. Scary stuff—and there are definitely advocacy issues involved. I set off an alarm at the Los Angeles airport on the way home. I have no idea if my proximity to all that Iodine 131 had anything to do with it.

Laura Weil is a member of the Health Advocacy faculty and the former Director of the Health Advocacy Program.

Faculty Profile: Jacqueline Hart

Jacqueline Hart earned a PhD in Sociology at the University of Pennsylvania and had a postdoctoral fellowship in health services research at the University of Pennsylvania School of Medicine and the Department of Veterans Affairs. She is a sociologist, ethnographer and activist who has worked in health and social justice in the U.S. and internationally for over 20 years. She was the Director of the Ford Foundation-funded Steps to Transforming Evaluation Practice for Social Change Initiative (STEPS) at Margaret Sanger Center International, Planned Parenthood of New York City (PPNYC), where she developed a planning, monitoring and evaluation resource for organizations around the world (www.stepstoolkit.org). Prior to that position she was the Director of Planning, Research, and Evaluation at PPNYC. In addition to social justice program learning, her work focuses on women’s and girl’s empowerment and well-being, inequality and health programs and policy. Jacqueline is very committed to thinking about and developing new ways for us to “see,” value, and productively utilize information about how social justice change happens. She is exploring ways to incorporate visual methodologies and art into purposive research and planning around ameliorating entrenched social inequalities and social problems and is currently collaborating on a project with the Center for Social Innovation at Adelphi University on food security among poor communities on Long Island, using participatory and visual techniques.

She teaches the Program Design and Evaluation course to second-year Health Advocacy students. In her course students learn the implications of a social justice framework for the entire program design and evaluation continuum, including the fundamental issue of how health problems are created and viewed. The emphasis is on how to create interventions that contribute to social justice through a thoughtful and inclusive iterative program learning process.

Faculty Profile: Cora de Leon

Cora de Leon earned an MSW and LCSW from New York University and an MPH from Columbia University. During 14 years of clinical and research experience, her clinical work has focused primarily on bereavement, while her research experience includes such topics as effectiveness of depression treatments and testing a cognitive behavioral intervention among active drug users. Ms. de Leon is currently involved in the management of data sets for several environmental health studies involving inner city children. She teaches research methods to graduate level students and enjoys bringing experiential learning into the classroom to show the applicability of research in everyday settings.

Publications by HAP Faculty

Testing Baby: The Transformation of Newborn Screening, Parenting, and Policymaking has been published by Rutgers University Press. The author, Rachel Grob, is a faculty member in the Health Advocacy Program, but is currently on two-year leave. The book draws on parents' experiences with newborn screening in order to examine its far-reaching sociological consequences. This cautionary tale also explores the powerful ways that parents' narratives have shaped this emotionally charged policy arena. Newborn screening almost always occurs without parents' consent and often without their knowledge or understanding, yet it has the power to alter family dynamics at the household level, the context of parenting, the way we manage disease identity, and how parents' interests are understood and solicited in policy debates.

The Economy Is Bad for Our Health…continued from page 1

We are just in the beginning stages of implementation of the Affordable Care Act and have only glimpses of its impact on access to health care. Several studies have reported that adults under 26 years of age are experiencing significant gains in obtaining health insurance as a result of the law, but it is unclear how much of the Act we will ever get to see unfold. As advocates, we know that the Affordable Care Act can make historic and important changes in the health care system, but there is much more work to be done to address the underlying causes of health disparities in our economic and political system. As the debate about how to address the recession continues, it is essential that economic justice and health concerns remain top priorities.

> *"There is much more work to be done to address the underlying causes of health disparities in our economic and political system."*

The Health Dangers of Fracking…continued from page 7

which is known to accumulate in milk. Texas has more natural gas wells than any other state in the union—76,436 to be exact—about the same number that the industry envisions for New York. Recently released figures indicate that the six counties with the most wells in Texas also have the highest incidence of breast cancer in the state.[4]

It seems quite clear that in their efforts to wring the last drops of fossil fuels from the earth and reap their rewards, the gas and oil industries are jeopardizing the health and well-being of us all. Please call Governor Cuomo at 1.888.884.1839 and tell him to make New York the first state in the U.S. to ban, forever, this costly and destructive method of energy extraction.

Polly Howells was a facilitator of the Pachamama Alliance's "Awakening the Dreamer, Changing the Dream" symposium, and is Chair of the Board of Bioneers, an environmental and social justice organization that produces a highly acclaimed 3-day conference every October in Marin County, California.

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[4] Heinkel-Wolfe, P. Breast cancer rate climbs up. *Denton Record-Chronicle*, Aug. 31, 2011.

STUDENT AND ALUMNI UPDATES

Elizabeth Bailey, first-year HAP student, author of *The Patient's Checklist* (Sterling Publishing Co., to be published in January 2012).

Barbara A Belhumeur, MA, CRC, HAP 2000, obtained a master's degree in Rehabilitation Counseling from Salve Regina University in 2011. Certified Rehabilitation Counselor 2011, Certificate of Advanced Graduate Studies (CAGS) in Mental Health Counseling candidate 2012. Post-graduate intern at Women & Infants' Hospital in Providence in Women's Day Hospital Program for Postpartum Depression. Eligible for state license in 2013, with plans for private practice counseling women in all levels of lifespan issues.

Julie Buyon, HAP 2005, remains deeply involved in end of life care. Director of services for MAC Angels, a foundation that supports patients with ALS and their families; vice president of the Westchester End of Life Coalition; New York State Long Term Care Ombudsman; advisor to the Centers for Aging in Place.

Marleise Brosnan, HAP 2009, Senior Business Unit Associate for AARP Legal Counsel for the Elderly (LCE), a nonprofit that champions the dignity and rights of Washington DC's elderly by providing free legal services to those in need. Her work focuses on management and administration of the organization's DC Office on Aging and DHHS Administration on Aging grants, managing the volunteer workforce and supporting the development office's strategic effort to lift LCE's profile through social media.

Jean Anne Cipolla, HAP 2007, instructor in the ALFUS Patient Advocacy Certificate Program through the University of Miami, teaching the Understanding the Patient Illness Experience course. Serves on the Board of Directors for the National Alliance on Mental Illness—Westchester; volunteer grief facilitator for the Tree House Program through the Bereavement Center of Tuckahoe.

Ashley Fletcher, HAP 2010, Client Services Associate at the Medicare Rights Center, a national, nonprofit consumer service organization that works to ensure access to affordable health care for older adults and people with disabilities.

Ashley Gephart, HAP 2010, Special Projects Associate at Planned Parenthood Hudson Peconic, a nonprofit regional health care provider dedicated to improving women's health and safety, preventing unintended pregnancies and advancing the right and ability of individuals and families to make informed and responsible choices.

Elizabeth (Liz) Givens, HAP 2011, Special Projects Coordinator for Families on the Move of NYC, a nonprofit children's mental health advocacy organization.

Tanya M Green, HAP 2007, coordinates and reports all Quality Assurance, Performance Improvement activities to the Regulatory Compliance Committee for JCAHO accreditation at the Department of Family Medicine at Bronx-Lebanon Hospital.

Jessica Hill, second-year HAP student, Case Manager at Parkchester Family Practice, The Institute for Family Health.

Susan Kingsbury, HAP 2010, volunteer at the Cheshire Medical Center-Dartmouth Hitchcock in Keene, NH, where she facilitates outpatient service for people requiring lab work; hopes to become a patient advocate in the CMC-DH emergency department.

Brenda Shipley, second-year HAP student, provided verbal and written testimony at a public hearing during Connecticut's 2011 Legislative Session, opposing a clause in a proposed health bill that was harmful to patients. Her letter to the editor was published in The Hartford Courant. The anti-consumer patient clause was removed from the bill before it was passed into law.

Lois S. Steinberg, HAP 2000, President of the Center for Aging in Place, an umbrella organization that provides resources to aging-in-place communities in Westchester County; board member of At Home on the Sound, The Volunteer Center and the Westchester End of Life Coalition.

Deborah Teevens-Gangl, HAP 2010, Senior Research Data Specialist in the Department of Medical Oncology at the Dana Farber Cancer Institute in Boston, focusing on the National Comprehensive Cancer Network (NCCN) study on breast cancer. The NCCN is a nonprofit alliance of 21 of the world's leading cancer centers and is dedicated to improving the effectiveness and quality of cancer care.

Betti Weimersheimer, HAP 2001, Executive Director of SPRYE (Staying in Place in Rye and Environs), a nonprofit that provides services, primarily through volunteers, enabling members to live safely, confidently and with dignity in their own homes while continuing to participate in community life.

Nicole Zolofra, HAP 2011, advocate in the Patient Centered Care department at NYU Langone Medical Center.

End-of-Year Reception

Meet Vicki Breitbart,
our new Health Advocacy Program Director

Panel Discussion with HAP Alumni

Thursday, December 15
6:30 p.m.

45 Wrexham Road, Bronxville

Please RSVP by December 7 to Crystal at
914.395.2602 or cgreene@sarahlawrence.edu