

with severely diminished capacities, she had had enough. Doctors were pressuring her for more interventions. She asked if the treatment would improve her life or if the doctors could guarantee that she wouldn't be readmitted to the hospital again. When her doctors couldn't give her positive answers to those questions, she told them she wanted nothing more than to die. Her wishes weren't received well by the doctors. If medical care for the elderly leaves a lot to be desired, then, as Bill Keller said in his piece in *The New York Times*, "nothing bedevils our discussion of health like the question of when and how to withhold it." It wasn't until we got palliative care staff to act as her advocate that my mother was transferred to hospice and got the kindhearted care she needed and deserved.

Even in hospice she risked having to be transferred because she wasn't dying fast enough. She was told she could linger for months and that this particular hospice was only designed for short-term care. A heroic physician explained that the only way she could be in control of her dying was to stop eating, with the knowledge that she would not have to suffer on her way to death. It was the most compassionate solution for my mother. With her family

surrounding her in a truly meaningful and dignified passing, she boldly chose this path.

If the elderly ill choose to live as my mother hoped to when she was in the rehabilitation facility, then we need a better system of coordinated care. If at some point the elderly choose to let go of life, we need a better system of supporting this choice. Patient advocates can play an important role with individuals and with changing a system that will give these choices back to the elderly individuals in need of care.

Board Appointments for Vicki Breitbart

HAP Director Vicki Breitbart is now on the Board of Directors of the National Association for Health Advocacy Consultants. She is also on the Advisory Board of Raising Women's Voices, a national initiative to make sure women's voices are heard and their concerns addressed as policymakers put the new health care reform law into action.

STUDENT AND ALUMNI UPDATES

Elizabeth Bailey, HAP class of 2014, presented and moderated a panel at the Solutions in Quality and Patient Safety 2012 forum hosted by the Greater Cincinnati Health Council. The Council connects hospitals, long-term care organizations and the community for discussions of health care issues.

Caroline Cancro, HAP 2012, began working at Jersey Mike's Franchise Systems in September. Her role is coordination of corporate charitable giving, as well as coordination with 550+ franchisees across the country to help them create better relationships with local charitable organizations. Jersey Mike's Franchise Systems is located in one of the New Jersey shore communities devastated by Hurricane Sandy. Caroline is helping to launch relief initiatives at Jersey Mike locations nationwide and at home, and is working to establish a 501(c)(3) charitable organization so they can better respond to the needs of the community.

Caroline (Lamontagne) Hall, HAP 1995, is trying her hand at consulting in Administrative Investigation/Advocacy after eight years in the health care sector and ten years in the federal government.

Jessica Hill, HAP 2012, is working as a case manager at the Institute for Family Health, where she assists patients in stabilizing resources such as medical care and prescriptions, food, transportation and other services. She also screens patients for NYC public assistance services and assists them in applying for Medicaid and Food Stamps.

Stacy Jacob, HAP 2011, is manager of Patient Experience at NYU Langone Hospital for Joint Diseases. In this role, she oversees the

Patient Representatives Department, Language Access Services, the Volunteer Services Department and the Gift Shop.

Beth Monkash, HAP class of 2013, will have a piece of non-fiction writing, "Doctor's Office Mad Libs," published in the upcoming anthology, *My Body, My Health: Women's Stories*.

Margaret Rubick, HAP 2010, has begun work as an anti-racism organizer and ally for justice. Her anti-racism work in Peekskill is in support of Darrell Davis, Committee for Justice and Kenneth Chamberlain, Jr. who is seeking justice for the shooting of his unarmed father, Kenneth Chamberlain Sr., by Peekskill Police. Margaret's letter to the Village of Sleepy Hollow in support of the move of Open Door, a health clinic for low-income people, was printed in *The Hudson Independent*. She also organized an Undoing Racism Workshop on the Sarah Lawrence campus in September.

Toi Scott, HAP 2011, is currently working as a community health organizer/education coordinator for the Sustainable Food Center (SFC), which works to cultivate a healthy community by strengthening the local food system and improving access to nutritious, affordable food. Her position involves helping parents and teachers organize into wellness teams and helping connect elementary schools to SFC's programs, such as farm to school (getting local, organic food into cafeterias), school gardens, basic organic gardening classes, cooking and nutrition classes for parents/families and health curriculum for students.

HEALTH ADVOCACY BULLETIN

The Journal of the Health Advocacy Program at Sarah Lawrence College

Volume 19 • Number 2 • Fall 2012

Letter from the Director

By Vicki Breitbart

My Mother Was Not Alone

It was a lovely day in May when I got the call that would change everything. My 93-year-old mother had been taken to the emergency room with excruciating pain across her midsection. Many of you have lived through something similar—an emergency situation with an elderly parent or even long-term illness of a parent—and know that I was about to enter the macabre and disorienting world of medical care and potentially long-term care for the elderly.

My mother had been living alone and was very independent. The hardest conversation we ever had was about taking away her car keys. Yet in the next few months I saw my mother's life savings drain away and saw her go from an active older adult to someone with limited hearing, sight and mobility, with recurring medical problems. She became someone who truly wanted to die. Those months brought home the difficulties of getting the comprehensive quality care needed for an ill older American.

Over the past century, the U.S. the population aged 65 or older has increased more than threefold from 4.1 to 12.9%.¹ Between 2010 and 2050, the number of Americans 65 and older is expected to more than double. This has been called the "silver tsunami" because our country's medical and social systems are totally unprepared to deal with this growing phenomenon.² The issues of aging have been on the periphery of health care for too long. As we can now look forward to the full implementation of the Affordable Care Act (ACA), it is still unclear what will happen with regard to care for the elderly. There are more measures for preventive care for the elderly in the ACA and these measures are necessary. But for those with medical problems, will anyone address the uncoordinated and badly managed care of the elderly ill?

The cost for care of the elderly is prohibitive. Along with the increase in the elderly population comes the growing number of persons with multiple chronic conditions. Chronic illness rep-

resents 83% of total U.S. health care expenditures and 99% of Medicare costs.³ More than half of Americans worry about their ability to pay for their health care costs as they grow older.⁴ During the Presidential election we heard a lot about the need to fix the Medicare system. The voucher idea looks like it was defeated with Obama's victory, but we don't know where Medicare will be cut. Can cost effective measures ensure that there is also quality, coordinated, patient-centered care for the elderly?

"The issues of aging have been on the periphery of health care for too long."

Immediately before my mother's surgery, we were told that there was only a 20% chance of survival. No one talked to my mother about what life might be like after this major surgery. My mother did survive, but the journey continued for several months through her medical recovery, rehabilitation, hospital readmission and finally hospice. With all my knowledge about the health care system, we still were caught in the irrational, uncoordinated and often chaotic care for the elderly ill and dying. The care my mother received in the rehabilitation facility was so badly coordinated that I had to call for a case conference, something that was usually done only to discuss discharge. As a result of the meeting, the staff learned more about my mother's nutrition, medication and plans for occupational and physical therapy than they had known during her stay at the facility.

The most distressing part for my mother was the response she got when she refused any further treatment upon readmission to the hospital. After months of rehabilitation and being at home

¹ Anderson, L.A., Goodman, R.A., Holtzman, D., Posner, S.F., Northridge, M.A., Aging in the United States: Opportunities and challenges for public health. *American Journal of Public Health*, March 2012, 102(3), 393.

² Ogden, L.I., Richards, C.L. Shenson, D. Clinical preventive services for older adults: The interface between personal health care and public health services. *American Journal of Public Health*, March 2012, 102(3), 419.

³ Partnership for Solutions. Chronic care: Making the case for ongoing care. 2010. <http://www.rwjf.org/files/research/50968chronic.care.chartbook.pdf>

⁴ Merrill Lynch. New retirement survey. 2005. New York: Merrill Lynch.

continued on page 12

Letter from the Editor

By Barbara Robb

You may have noticed that this issue of the *Bulletin* arrived in your mail boxes later in the year than usual. The reason? We waited until after the election results were in before finalizing the issue. Whether implementation of the Affordable Care Act would, or would not, occur depended upon those results. It is with great relief that we now look forward to full implementation of this important Act.

Policy is a major focus in this issue. Joshua Lapps writes about his work in regulatory and legislative advocacy at the Society of Hospital Medicine. Pam Willrodt describes the policy aspects of her VISTA work in South Carolina. Katherine Special attended the Civil Liberties and Public Policy Conference on reproductive justice as a student representative of HAP. Leslie Anagnostakis writes about environmental justice and national chemical policy reform. Her article is part of our continuing coverage of HAP's involvement with Mossville Environmental Action Now (MEAN) in Louisiana, as is the article by Laurel Cates about the Mossville Environmental Health Fair.

HAP has been active in other ways, too. The program hosted its first Health Advocacy Careers Roundtable and partnered with the Center for Continuing Education in hosting a certificate program in Mediation in Health Care. Numerous forums were held, including one by acupuncturist Ian Koebner. Jim Pastore is our Point of View contributor for this issue; he writes about Koebner's talk and the use of acupuncture for relief of chronic pain.

And of course we haven't overlooked the important role of personal experiences. Debra Finkelstein writes about her internship at the online magazine *Pulse—voices from the heart of medicine*. Last, but far from least, Vicki Breitbart eloquently describes the difficulties faced in obtaining adequate care for ill seniors.

The majority of the readers of the *Bulletin* live in the area that was affected by Hurricane Sandy in October. I'm sure I speak for all of us at Sarah Lawrence in hoping you didn't sustain too much inconvenience or damage to your homes or workplaces. Our thoughts are with all those who continue to suffer from the effects of the storm.

www.slcc.edu/health_advocacy

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

Program Director: Vicki Breitbart

Editor: Barbara Robb

Email: vbreitbart@sarahlawrence.edu

All material in the *Health Advocacy Bulletin* is the property of the authors and may not be reprinted without permission. Opinions expressed are not necessarily those of the editor or of the Health Advocacy Program.

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

Letter from the Director: My Mother Was Not Alone	1
Letter from the Editor	2
Reports from the Field	3
Health Policy as Health Advocacy at the Society of Hospital Medicine	3
One Life after HAP: VISTA in South Carolina	4
Environmental Justice and National Chemical Policy Reform	5
Mossville Environmental Health Fair	6
Civil Liberties and Public Policy Conference on Reproductive Justice	7
Internship at <i>Pulse</i>	8
Point of View: Pain Relief: Does Acupuncture Work?	9
Health Advocacy Program Events	10
Health Advocacy Careers Roundtable	10
Certificate Program in Mediation in Health Care	11
Student and Alumni Updates	12

The MA in Health Advocacy Program is supported by: The Fund for Sarah Lawrence

REPORTS FROM THE FIELD

Health Policy as Health Advocacy at the Society of Hospital Medicine

By Joshua Lapps

The need to heal the health care system may not be of the utmost immediate concern to the experienced, patient-focused doctor. Yet, this fundamental challenge—that physicians must pursue simultaneously with the considerations of patient care and systems change—makes working in a medical society incredibly rewarding.

The richness of the Health Advocacy Program is highlighted in the multi-disciplinary coursework that encourages critical thinking and connecting individual experiences with systems-level change. It is this perspective that brought me to the Government Relations Specialist position at the Society of Hospital Medicine (SHM).

SHM is a specialty medical society that represents the interests and perspectives of hospitalists. Hospitalists are part of a growing field that includes hospital-based internal medicine physicians and, increasingly, physicians who practice in a myriad of other non-outpatient medical institutions.

"...understanding power dynamics is vital to advocacy."

The organization is particularly focused on improving the quality of care and the quality of transitions of care for patients; hospitalists grew out of an expanding gap between hospitals and outpatient physicians who were, and continue to be, rounding in the hospitals less and less. To this end, SHM has a variety of programs aimed at tackling some of the most complex challenges in medicine: care transitions and readmissions.

Similarly, the areas of federal policy SHM currently devotes the most resources to are health systems reform, quality improvement programs, health care research and health information technology. It is abundantly clear that the health care system needs reform, and these reforms should be rooted in best practices designed to improve the outcomes and experiences for patients. In practice, this means that quality measurement programs of physicians, for example, should provide useful feedback that enables an individual practitioner to continuously improve the quality of care she provides.

In my role at SHM, I cultivate the grassroots advocacy of the membership as well as conduct policy analysis on a range of policy initiatives related to health care. Like most other medical societies, SHM engages in both legislative and regulatory advocacy, leveraging its expertise and influence to push for sensible initiatives designed to improve the delivery of and access to care. In practice, I spend a great deal of time reading and analyzing legislation and regulatory rules and devising ways to communicate them more succinctly and accessibly.

Health policy advocacy affords a fascinating vantage point on the political and policy development processes and an opportunity to see firsthand the role of special interest groups in shaping the health care system. The myriad of actors in policy development all exert influence and power over the processes, but are often competing for scarce resources and attention in an increasingly frenetic policy world.

While the perspective and experiences of physicians are at times divergent from those of patients, many practitioners are as frustrated with the limitations and malformations of the health care system as the patients who seek care. It is this frustration that led SHM to orient itself around the improvement of patient care; the path to professionalization for the specialty is paved in health care change.

One of the greatest barriers that I face in my work is not a lack of interest in policy among the membership. Physicians often overwhelmingly cite advocacy as being an integral part of their scope of influence. However, the irregular patterns of advocacy and the sometimes intractable complexity of policy issues make it difficult to establish and sustain prolonged advocacy efforts. As a result, I am focusing on building a culture of advocacy, wherein the boundaries between practicing medicine and high-level policy advocacy blur somewhat to create a more seamless way for physicians to act.

As often discussed in HAP, understanding power dynamics is vital to advocacy. In sharp relief to a society that seeks stark contrasts, there is a variegated texture of power dynamics between patients, physicians and the health care system. Many physicians see the problems in their institutions and the health care system, but feel or are powerless to act. Much of my work is to help collate these physician perspectives and provide an outlet for influencing policy outcomes. Ultimately, sustainable policy change must come from a variety of sources that include the voices of professionals, patients and other stakeholders.

Joshua Lapps is a graduate of the Health Advocacy Program.

Sayantani DasGupta and Linda Koebner featured in Sarah Lawrence Magazine

The theme of the fall 2012 issue of *Sarah Lawrence* magazine was The Will to Live. Sayantani DasGupta contributed an article about the importance of narrative in health care. Linda Koebner and her therapy dog, Spirit, were featured in an article about their work at Montefiore Medical Center. If you didn't see the issue, look for it at <http://alum.slcc.edu>.

One Life after HAP: VISTA in South Carolina

By Pam Willrodt

It was that darn book that made me do it. I had no intention of yet again becoming a full-time volunteer (paid at \$927 a month), especially after two years at Sarah Lawrence College. The book? *Common Fire: Leading Lives of Commitment in a Complex World*, by Daloz, et al. Why did I read it? I chose it from an assigned reading list in Capstone Seminar. What did it cause? It led me to apply for and become a VISTA—a Volunteer in Service to America, considered to be the domestic Peace Corps (I had completed the real thing about five years ago in Guyana, South America). I felt the overwhelming need to serve again and tried to talk myself out of this, as did my friends. But jobs that fit me and my passions (kids, health, education, the under- or un-served) were few and far between. And this was a job that was perfect—developing a health literacy program from scratch in Charleston, S.C.

“This is my work now—helping to develop sustainable health literacy initiatives.”

I work for the Charleston Promise Neighborhood (CPN), a not-for-profit organization that believes: “All children deserve to grow up in communities that are healthy, vibrant, and filled with opportunity. Our purpose, and our promise, is to make this a reality for every child who lives within the Charleston Promise Neighborhood.” CPN is an organization founded on the Harlem Children’s Zone model; it is a Promise Neighborhood.

The Promise Neighborhood vision is that all those growing up in Promise Neighborhoods have access to great schools and strong systems of family and community support that will prepare them to attain an excellent education and successfully transition to college and a career. The purpose of Promise Neighborhoods is to significantly improve educational and developmental outcomes in our most distressed communities. And the 5.6 mile area that is the CPN is truly one of those most distressed. Almost 73% of the people living in the CPN live at or below 125% of the Federal Poverty Level, the eligibility threshold for SNAP (Supplemental Nutrition Assistance Program) benefits in South Carolina. Educational levels are low: 27% have no high school diploma or equivalency; another 32% have completed only high school.

All of my work here in Charleston (about 1.5 months so far) is based on a combination of past experiences, including my public health coursework, as well as the SLC Health Advocacy Program. Papers written for HAP followed the basic themes of Children, Health Equity (versus Equality) and the Social Determinants of Health—not quite Social Justice, but more about important voices not heard as often as perhaps they should. This is my work now—helping to develop sustainable health literacy initiatives in an organization working on behalf of and for “my people.”

In my short time at CPN, I have researched, researched and researched some more (thank you, History of Health Care and Program Design). My theory of change and logic model is thorough

and envisions outcomes until 2030 following an iterative, cross-disciplinary, life-span approach (models completely supported by the literature). I take into consideration the distal factors that contribute to health literacy (social and environmental determinants) as well as those proximate (personal and situational determinants). I’ve needed to understand the people whose voices I seek to reveal—this through data mining/analysis and interviews where I listen much more intently to the narratives told, hearing through the words (taking Illness and Disability Narratives in a bit of a different direction but using its concepts nonetheless).

Policy, Law and Ethics also have played important roles in my work. I’ve researched, analyzed and made recommendations on the applicability of HIPAA (Health Insurance Portability and Accountability Act) versus FERPA (Family Educational Rights and Privacy Act) privacy laws as they relate to school health clinics so that data can be more readily available for analysis and resource determination. The applicability of federal and state law is crucially important to the situation in the CPN—South Carolina does not accept a great deal of federal monies, impacting programs and lives throughout the state. How ethical is this (not clinical ethics, but extensions of those ethical concepts) for people who live here who cannot get the same Medicaid coverage as those in other states or for schools that do not have access to No Child Left Behind funds?

My knowledge of voice comes from *Models of Advocacy*; my passion for the work comes from the variety and expanse of my life experiences. This passion has come across to individuals both in and out of CPN and has helped to create fabulous partnerships where limited resources can be leveraged for the good of our community. The local library, where children spend a great deal of after school time, and I are going to work together to develop health literacy programs and may even purchase some new and applicable books to broaden the way they think about health. Not just learn about it—that is health education; but truly think about it, asking questions, to understand the Why, not just the What—this is health literacy. And in a meeting with The Citadel and College of Charleston (CofC) to begin to set up an evaluation program across all the CPN interventions, my passion and work were recognized as I told the stories of the neighborhood from both a data and people perspective; I am now going to help with the syllabus for a new undergraduate Public Health degree at the CofC and have been asked to lecture in the class discussing health literacy and its effect on access to care.

While I had originally thought that getting a paying job after HAP was much more logical than becoming a VISTA, I now know that this position is exactly right for me, my skills, my education, my experiences and my passions. “Leap and the net will appear” (John Burroughs). What a fabulous net I have fallen into!

Pam Willrodt is a graduate of the Health Advocacy Program.

Environmental Justice and National Chemical Policy Reform

By Leslie Anagnostakis

Two years ago when I was considering applying to the Health Advocacy Program at Sarah Lawrence, I read a series of compelling articles in the *Health Advocacy Bulletin*. HAP students and faculty, including Gloria Escobar-Chaparro and professor Rebecca Johnson, wrote about the environmental justice work they were doing in Mossville, Louisiana. Around the same time, Dr. Sanjay Gupta presented an investigative report on CNN about environmental health problems in Mossville that were being ignored by government agencies and industrial companies. Inspired by the actions HAP students and faculty had taken to support a community so far removed from New York, I enthusiastically applied and was accepted to the program. My first year of coursework ended with a unit on environmental health advocacy in *Models of Advocacy: Theory and Practice*. I wrote my final paper about Mossville and then, somewhat serendipitously, my summer internship evolved into building a case for national chemical policy reform based on the environmental injustice in Mossville.

At the end of the spring semester, Rebecca Johnson was looking for students to help Mossville Environmental Action Now (MEAN) prepare for an upcoming health assessment fair in Mossville. I was hoping to create a summer internship of environmental justice advocacy work. She introduced me to Mark Mitchell, MD, MPH, another advocate working with MEAN, and he agreed to be my internship supervisor. Dr. Mitchell is the president of Mitchell Environmental Health Associates, a consulting firm on environmental health and environmental justice issues. For the past fifteen years he has worked primarily with low-income communities and people of color on environmental health and justice issues. More recently he has become involved in chemical policy reform efforts at the national level.

The environmental health movement has focused to a great extent on our country’s current chemical safety law, the Toxic Substances Control Act (TSCA) of 1976, for its inability to protect us against damaging health effects of toxic chemicals. When TSCA was enacted, 62,000 chemicals were “grandfathered” in without requiring safety testing. Since then, chemical production has increased dramatically. Of the 80,000 chemicals currently on the market, less than two percent have been evaluated by the EPA for health and safety risks and only five chemicals have been banned. Despite increasing rates of health problems linked to dangerous chemicals and growing concerns about chemical safety, TSCA remains unchanged and ineffective in protecting our nation’s health. The President’s Cancer Panel of 2010 prepared an analysis of the current state of the “War on Cancer,” and concluded by confirming that “exposure to toxic chemicals is an important and under-recognized risk factor for cancer.” The Panel recommended that the government take immediate action to overhaul our nation’s flawed chemical management system.

In 2011, the Safe Chemicals Act (S. 847) was introduced by Senator Frank Lautenberg (D-NJ) to protect against the effects of harmful chemicals. This legislation begins to address the envi-

ronmental health risks we all face by requiring health-based safety testing of all chemicals before they are allowed into commerce. It provides for health and safety information on chemicals to be made public so that consumers can make informed decisions about their health, and for establishment of protective measures to reduce the disproportionate chemical exposure of vulnerable communities like Mossville. The legislation is in committee at this time.

“[the Toxic Substances Control Act] remains unchanged and ineffective in protecting our nation’s health.”

The State of Louisiana is especially important in reform efforts. Not only is it one of the largest chemical producing states in the country and one of the most polluted, but Louisiana State Senator David Vitter is a staunch advocate for the chemical industry and an influential member of the Committee on Environment and Public Works. Dr. Mitchell and I presented a publicity campaign proposal to Safer Chemicals, Healthy Families (SCHF), the largest chemical safety group in the U.S. The campaign focused on Senator Vitter’s record of action in support of the chemical industry at the expense of public health. It also highlighted the unethical behaviour of Louisiana’s flame retardant companies who engaged in deceptive and unethical tactics to shield their products from health protections and justify flame retardant mandates. They intentionally misrepresented scientific evidence about the effectiveness and health risks of flame retardant chemicals and hired a burn surgeon to tell fabricated stories to legislators about children dying in fires due to lack of flame retardants. They created their own advocacy group called Citizens for Fire Safety whose membership consisted solely of representatives from companies producing flame retardants.

In addition to working with SCHF, Dr. Mitchell is a strong voice on environmental health and justice within the National Medical Association (NMA), the oldest and largest medical organization representing African American physicians. With his support and direction, the NMA has been a leading advocate on environmental justice issues. My work for Dr. Mitchell supported these efforts, some of which included drafting resolutions, preparing materials for Congressional briefings and conferences, and writing newspaper articles and letters to senators.

In my first conversation with Dr. Mitchell he gave me a list of assignments—on topics that I knew nothing about—with deadlines that required staying up until all hours of the night. Most of the time I didn’t think I was qualified to do the work and I was sure Dr. Mitchell was just giving me educational exercises with no intention of using anything I wrote. But this was not at all the case. One of my assignments was to draft talking points for the president of

continued on page 6

the NMA to present on a national teleconference. Later, when I was listening to the teleconference, I was so surprised that the president read my exact words. I have to thank HAP for those dreaded worksheets and papers I had to write, because they really helped prepare me for this internship.

Two years after Rebecca and Gloria reported in the *Bulletin* on their work with MEAN in trying to convince the EPA, the Louisiana Department of Environmental Quality (LDEQ), and the chemical companies to reduce the amount of pollution being emitted from industrial facilities, MEAN is still fighting the same battle. Most recently, when Georgia Gulf, a major vinyl chloride manufacturer, applied for a permit to expand its Mossville facility, MEAN protested based on documentation that Georgia Gulf had been consistently violating air emission standards for the past five years. Despite MEAN's actions and the company's own admission

of violations, as well as their refusal to improve emission controls because of "prohibitive costs," the LDEQ approved the Georgia Gulf permit.

The chemical industry is not held to even a reasonable standard that will protect the health of the communities where their facilities are based. Comprehensive reform must include a focused plan for reduction of toxic chemical exposure in communities like Mossville. New policies should address the health risks posed during the entire life cycle of a chemical—production, distribution, use and disposal. They should include creating buffer zones between residences and industrial sites and waste sites, requiring emissions monitoring on an ongoing basis and enforcing ambient air standards. Reform must give the EPA the power to regulate and implement these policies so that environmental justice communities can be heard.

Leslie Anagnostakis is a graduate student in the Health Advocacy Program.

Mossville Environmental Health Fair

By Laurel Cates

In the 1950s chemical processors and companies producing vinyl chloride for siding opened plants in Mossville, promising jobs to people in the community. Ever since, these companies have been releasing toxic chemicals—dioxin, vinyl chloride, benzene and ethyl chloride—into the town's groundwater, soil and air. Children living in Mossville have developed asthma and other respiratory ailments, and young women often develop endometriosis. There have been high rates of premature deaths from cancers associated with these chemicals, as well as kidney and liver disease.

disease is associated with dioxin) and also had esophageal cancer. Toxin-related illness is pervasive in Mossville and is always weighing on citizens' minds.

The health fair was a result of a collaboration between MEAN, Sarah Lawrence College, The Subra Company, the University of Texas Health Science Center at Houston, Southwest Center for Occupational and Environmental Health and Mitchell Environmental Health Associates. The fair is part of an ongoing strategy to more closely associate health effects with toxic exposures. It is remarkable that this small town has enlisted the help of so many knowledgeable, influential people and organizations with know-how to advocate for them in their cause.

Dr. Mark Mitchell conducted the second in a series of workshops for local physicians on taking environmental health histories to establish which toxins a person may have been exposed to through work or at home. These innovative environmental justice educational activities will be supported in the coming year by an EPA grant.

Teamed with MEAN members, Gloria and I presented attendees with informed consent forms giving permission for their blood to be drawn. Members of the community had their health histories taken and then blood drawn by Dr. Carson, who also supplied test tubes for blood collection, a centrifuge and other equipment. All blood samples were then sent to be tested by a local lab under the auspices of the University of Texas Occupational Health Center. Wilma Subra organized an exhibit and gave out handouts listing which companies released particular toxins and the part of the body subjected to harm by each toxin.

A goal of MEAN for the future is to open an environmental health clinic where patients can have their health histories taken, followed by blood tests measuring the levels of specific toxins in their blood. The specific toxins to be tested will be determined by their

continued on page 7

"Environmental activism is a slow process."

Mossville Environmental Action Now (MEAN) was established by leaders in the community in the mid-1990s. One of its goals is to compel federal and state environmental agencies to enforce and strengthen existing standards for release of toxins in the community. In August I traveled to Mossville with HAP faculty members Rebecca Johnson and Gloria Escobar-Chaparro to help set up and participate in an environmental health assessment fair organized by MEAN. I volunteered because I wanted experience seeing how an environmental justice organization functions. My interest was piqued when I saw the environmental pollution in Mossville in the film *Blue Vinyl* and when I read in Sandra Steingraber's *Living Downstream* how companies produce toxic products and expose Americans to them with impunity.

We began our trip by knocking on doors and handing out fliers about the health fair to people in town. We only had time to knock at a few houses, but it unnerved me to find that I immediately met people who told me that their children had breathing problems. One man with yellowed eyes told me he was on dialysis (kidney

health histories. Ultimately, anonymous results from these tests will give an aggregate picture of the community's exposure, a powerful tool in contradicting claims of the industrial sector that no community members are harmed by their activities. Thanks to a generous contribution of equipment from the Lower 9th Ward Clinic (New Orleans), this goal is closer to reality.

Speaking with residents in the town, I was struck by how torn members of the community are. They feel a great attachment to this, their hometown of many generations. One young woman told me that there were five generations of her family living in Mossville until last December, when her grandmother died. On the other hand, they know living in Mossville is killing them. Even as they are trying to establish the health clinic, residents also speak of being bought out by the chemical companies and using that money to move to a safer and healthier community. As the chemical companies want to expand deeper into Mossville, they may buy the polluted homes of remaining residents.

In our Models of Advocacy class we learned that many companies change policies only when it affects their bottom line or when

forced to by government regulation. This is so evident in Mossville. At a community meeting last June, residents had the opportunity to confront a representative from the Louisiana Department of Environmental Quality regarding a permit renewal requested by Georgia Gulf (an offending company) and a request to expand the plant. Residents also protested a false notation on Georgia Gulf's application specifying that a location with several houses close to the fenceline was uninhabited. The company's emissions of vinyl chloride have exceeded ambient air quality standards for 10 years. As a result of citizens' pointed questions demonstrating knowledge of the facts, Georgia Gulf was asked to price out the cost of reducing fugitive emissions. The company replied that it was not financially feasible to cut the emissions. Although the permit has been granted, it is being appealed by MEAN.

Environmental activism is a slow process, but with MEAN members persevering despite seemingly insurmountable odds and collaborating with reputable partners, progress is being made.

Laurel Cates is a graduate student in the Health Advocacy Program.

Civil Liberties and Public Policy Conference on Reproductive Justice

By Katherine Special

The Health Advocacy Program was a sponsor of the April 2012 Civil Liberties and Public Policy Conference (CLPP) hosted by Hampshire College in Amherst, Massachusetts. The theme of this year's conference was From Abortion Rights to Social Justice: Building the Movement for Reproductive Freedom. The fieldwork requirement I was completing at Raising Women's Voices focusing on women's health, combined with my interest in social justice, inspired me to attend the conference. It was an excellent opportunity to explore my own interests, as well as to build on the knowledge I was gaining from my internship in women's health and rights. I also anticipated that the conference would add to the knowledge I had gained from my first year in the Health Advocacy Program. I was happy to attend it as a student representative of HAP and to be able to bring back what I had gained and experienced to the rest of my classmates. Before attending the conference, I had expected the focus to be limited to reproductive issues, but I was pleasantly surprised to learn that the topics were much more broad and viewed health in a more holistic paradigm.

The opening of the conference was one of the most striking experiences, not only because of the content being covered but also because of the passion being displayed and felt throughout the room. I felt immediately that I was in a community of advocates and activists who, despite their various backgrounds, were all united by a social justice calling in their lives and work. I was also highly impressed that non-English speakers presented in their native languages without translation, which to me showed a great deal of respect for other languages and cultures. After the opening presenta-

tion, it was clear to me that this conference was going to cover a lot more than just reproductive issues, reflecting the reality that health issues are multifactorial and socially impacted. The conference attendees themselves were equally impressive. I found them to be very open minded and eager to become more involved in social justice issues. The majority of attendees were of college age, which said to me that there is a growing interest among younger generations for social justice and enthusiasm about learning how to work for collective change.

"Witnessing the enthusiasm of the young participants... has inspired me to work with adolescents."

I chose to attend the following four workshops: racism and white privilege, use of different narratives in social justice promotion, a career building session and an information session on transformational justice. Like the Health Advocacy curriculum, the topics covered more than just health and extended to broader social issues that impact health, such as race, socioeconomic status and gender. The phrase that stuck with me the most was from the narratives session. It was to "challenge the dominant narrative" by introducing alternative narratives that include voices that are commonly excluded. In the Health Advocacy Program we are taught from the beginning

continued on page 8

not to use our own voices and experiences to speak for others, but instead to use our knowledge and skills to promote the voices of others. The workshop on racism and white privilege related to the use of alternative texts and articles in the Health Advocacy program to address the lives and experiences that are commonly overlooked. For example, in our History of Health Care class we read a text on the healing and medicinal practices on slave plantations, showing that although the dominant medical experience excludes these types of traditional practices they did in fact influence our current understanding of medicine.

One of the most important experiences I took away from the conference was inspiration for my capstone project, an opportunity for

HAP students to apply our gained academic knowledge and acquired professional skills to address a health issue. Witnessing the enthusiasm of the young participants at the conference has inspired me to work with adolescents in order to address their health care issues. Although I am still working on the specific details of my project, I am confident that I can use my experiences in Health Advocacy and inspiration gained from the conference to make a difference in the lives of adolescents. I would highly encourage other Health Advocacy students to take advantage of academic conferences as supplemental opportunities to further the multi-disciplinary knowledge gained through the Health Advocacy Program at Sarah Lawrence.

Katherine Special is a graduate student in the Health Advocacy Program.

Internship at *Pulse*

By Debra Finkelstein

*“May these words serve as encouragement...for silence has never brought us anything of worth.” –Audre Lorde, *The Cancer Journals**

My internship with *Pulse*—voices from the heart of medicine, the free, weekly online magazine, reinforced what many discover in Sayantani DasGupta’s Illness Narrative’s class: everyone has a health care story, from the family doctor who has been practicing for forty years to the teenager with a broken arm walking into an emergency room for the first time. We all have a story. We all have a voice.

“As health advocates, we have a responsibility to share the stories and experiences of individuals in our communities.”

Pulse uses personal stories and poems written by patients, family members, nurses, doctors and other health care professionals. It provides a place for them to talk honestly and candidly about giving and receiving medical care. *Pulse* delivers a short story or poem each Friday by e-mail—a personal account in words that are heartfelt, moving and inspiring—in a refreshing change from the usual dialogue surrounding health care.

Written from a first-person perspective, the aim of the stories and poems in *Pulse* is to share an experience “from the heart” in a way that is cathartic and healing. A powerful example of the healing ability of a story is provided by one of the most popular and commented on submissions, *Babel: The Voices of a Medical Trauma*, by Tricia Pil, M.D., who wrote about the events surrounding the birth of her third child.¹ Alternating between her version of the experience as a patient, the version in her medical record and the hospital

administration’s response to her letter of complaint, the story allows the reader to see how each point of contact could be interpreted in different ways. As a result of the trauma she experienced, Dr. Pil was unable to practice medicine for several years. She rediscovered her love of writing and wrote this story, which allowed her to begin healing. According to Dr. Paul Gross, the editor-in-chief and founder of *Pulse*, having her story published in *Pulse* helped Dr. Pil heal. Her story allowed readers to share with each other and the author—which does not happen often—creating a space where many readers commented that they no longer felt isolated or alone.

During my internship, I worked with many of the contributors to *Pulse* in preparation for the release of the second *Pulse* anthology, *More Voices*. I contacted the nurses, residents, doctors and other health care professionals who contributed to *Pulse*. The image of the harried, cold, emotionless health care provider is the dominant and common narrative in today’s society. My work with these giving individuals revealed the opposite. Here was the humanism in medicine. Many of the patients, family members and caregivers I worked with were thankful for the opportunity to tell their stories and share their voices. *Pulse* has truly created a caring community.

I believe that *Pulse* is inspiring and insightful for professionals in the health advocacy field and I invite you to join me and the *Pulse* community by subscribing to this free weekly e-magazine at www.pulsemagazine.org. As health advocates, we have a responsibility to share the stories and experiences of individuals in our communities. We have to bring forward the voices of those who are unable or unwilling to speak or do not yet have a voice so that we can learn from each other and those around us. *Pulse* is there for us and the patients, families, friends and neighbors we care about and work with—for anyone who has been touched by the health care world. *Pulse* welcomes a diversity of voices and readers—and it is only through this sharing that *Pulse* can continue to bring a range of perspectives and humanity to the health care conversation.

My work with *Pulse* has provided me with a microcosmic view of health care. It has reaffirmed that there are other sides to medi-

continued on page 11

POINT OF VIEW

Pain Relief: Does Acupuncture Work?

By Jim Pastore

Ian Koebner, pain expert and acupuncturist, addresses an informal HAP forum

Acupuncture may seem mysterious to many people in the U.S. But most Americans who visit an acupuncturist are looking—sometimes desperately—for help in reducing an all-too-common ailment: chronic pain.

To find out if acupuncture “works” for pain-relief—and to learn more about the role of this ancient but often misunderstood form of complementary and alternative medicine (CAM) in today’s U.S. healthcare system—the Health Advocacy Program at Sarah Lawrence College invited pain expert and licensed acupuncturist Ian Koebner to speak at an informal HAP forum entitled “Does Acupuncture Really ‘Work?’”

Mr. Koebner’s unique skill set bridges eastern and western approaches to the complex problem of pain. He holds a Master of Science in Pain Research, Education, and Policy from Tufts University School of Medicine and a Masters in Acupuncture and Oriental Medicine from the New England School of Acupuncture, and is licensed and registered to practice acupuncture in California and Massachusetts.

Does Western medicine need a new paradigm for dealing with pain?

Chronic pain is an “enormous burden,” Mr. Koebner said, and according to an Institute of Medicine (IOM) report, “addressing the nation’s enormous burden of pain will require a cultural transformation in the way pain is understood, assessed, and treated.”

The nature of pain has prompted people to seek relief outside mainstream Western medicine. “Pain is not just a sensory phenomenon,” Mr. Koebner explained. There are many instances when a patient experiences pain and yet, the diagnostic tools and techniques at the disposal of Western medicine may not see its cause. “Fundamentally, it is a subjective, emotional experience. And, therefore, there is no purely objective measure for it. Perhaps the most useful definition for pain is: What the patient says it is.”

Mr. Koebner said he was glad to see bold language in the IOM report calling for a “cultural transformation.” “That is a pretty strong statement for a government document,” he said, dryly. “It’s really calling for a restructuring of the way pain is taught, assessed, treated and researched.”

Acupuncture use in the U.S. rises 32% from 2002 to 2007

Acupuncture is defined by the National Institutes of Health, the U.S. Food and Drug Administration and others as a “whole system” of medicine. Traditionally, acupuncturists have served as primary care practitioners, treating a whole range of conditions. Whether in Asia or the U.S., acupuncturists go beyond treating sickness, and work with patients to promote wellness.

With roots in Asian immigrant communities, acupuncture in the U.S. burst into wide public consciousness in the 1970s, when *New York Times* columnist James Reston wrote about receiving

acupuncture while covering Richard Nixon’s famous trip to The People’s Republic of China. Reston’s appendix burst and his post-operative pain management included needles inserted into his skin. According to Mr. Koebner, Reston’s article ignited a great deal of interest in acupuncture in the U.S.

Fast forward to 2007, when the National Health Interview Survey (NHIS) reported that the number of adults visiting acupuncturists increased 32 percent from 2002 to 2007. Fully 3.1 million people underwent acupuncture in the last year of the survey. Most people had between one and 10 treatments, and 72 percent of the sample population received “some” or a “great deal” of help in resolving their primary complaint. Eighty percent of those visits involved pain management.

Of the many reasons that people undergo acupuncture, the most widely accepted in the biomedical community is analgesia. Mr. Koebner explained that “researchers have found plausible biomedical reasons for its efficacy” in relieving pain. Mr. Koebner focused the bulk of his presentation on acupuncture’s use as an analgesic for low back pain. At least 85 percent of low back pain cases are termed “idiopathic,” meaning that physicians can identify no physical cause for the pain. “This doesn’t mean it’s not real, or it’s a low level of pain,” he said. “It could be 10-out-of-10 excruciating pain.” In Western countries, 70 percent of people experience back pain. Most episodes, Mr. Koebner asserted, resolve without treatment.

Mr. Koebner described two high-quality studies performed with German patients. One study showed that acupuncture is more effective than conventional therapies (including drugs and physical therapy) for chronic low back pain. The second study showed that acupuncture, when used in combination with routine medical care, is more effective for low back pain than routine medical care alone. These significant studies led to integration of acupuncture into the German National Health Service. Acupuncture, performed by medical doctors, is now a covered procedure in the German health care system.

“A reasonable referral option for patients with chronic pain”

Students in the Health Advocacy Program, perhaps more than others, recognize that people go to alternative and complementary practitioners—such as acupuncturists—for a host of reasons. Perhaps one reason is the expectation that traditional practitioners will offer more of the qualities that are underrepresented in conventional medicine, such as an emphasis on the doctor-patient relationship, compassion and a healing presence.

Health advocates also should be aware of advances made by conventional researchers in demonstrating the efficacy of traditional medical systems, such as the efficacy of acupuncture in treating low back pain and other maladies. A recent peer-reviewed article, “Acupuncture for Chronic Pain,” appearing in the September 2012 *Archives of Internal Medicine*, contained important findings on the

continued on page 10

HEALTH ADVOCACY PROGRAM EVENTS

Health Advocacy Careers Roundtable

The Health Advocacy Program hosted its first Health Advocacy Careers Roundtable on June 8th. This day-long event provided a venue for those interested in learning more about Health Advocacy to network with health advocates working in a variety of roles, and to engage in discussions about relevant issues.

The Sarah Lawrence Master of Arts Program in Health Advocacy has been in existence since 1980, but it is only recently that there has begun to be a wider understanding of how valuable—and important—health advocates are and how broad a range their work covers. Many know that health advocates work in direct patient advocacy, whether as patient representatives in hospitals or helping individual patients and families understand and negotiate medical bills or navigate the bizarrely complex U.S. health care system. What's not as well known is that health advocates work in almost every environment where the health of an individual or the community can be affected.

The Roundtable day began with opening remarks by **Vicki Breitbart**, Director of the Health Advocacy Program, who has had an impressive, multifaceted career working as an advocate in a variety of settings, including a hospital and not-for-profit organizations working for reproductive and women's rights and against intimate partner violence. Next was a panel discussion with several health advocates:

Ethlouise Banks, Patient Representative, Memorial Sloan Kettering Cancer Center;

Liz Breier, Program Director of Family Support for Families on the Move of NYC, Inc.;

Sheila Reynertson, Advocacy Coordinator, MergerWatch Project;

Laura Weil, Patients' Rights Advocate, Advisory Committee on the Medical Uses of Isotopes, United States Nuclear Regulatory Commission (and former Director of HAP); and

Gloria Escobar-Chaparro, consultant for Mossville Environmental Action Now (and HAP fieldwork coordinator).

The panelists described their career paths and journeys, as well as their day-to-day advocacy roles.

Next up on the agenda was the World Café—an activity which gave each participant the opportunity to have a 10 minute discussion with Vicki Breitbart and each of the panelists. Lunch allowed participants and panelists to have longer, more personal discussions about their work and the health advocacy field. In the afternoon, participants were divided into groups led by the panelists where they reviewed some case studies in health advocacy, followed by an engaging group discussion of the participants' perceptions of what the role of a health advocate might be in each of the scenarios.

We were thrilled that the number of participants was higher than expected, with every attendee rating the event good or excellent. Keep your eyes open for the next Health Advocacy Careers Roundtable event!



From left: Ethlouise Banks, Gloria Escobar-Chaparro, Sheila Reynertson, Laura Weil, Vicki Breitbart. (Panelist Liz Breier was not present for photo.)

For More Information

The National Center for Complementary and Alternative Medicine (NCCAM)

Part of the U.S. National Institutes of Health (NIH), NCCAM undertakes research, training and dissemination of data to the public and professionals.

National Certification Commission for Acupuncture and Oriental Medicine (NCCAOM)

A private non-profit organization, NCCAOM validates entry-level competency in the practice of acupuncture and Oriental medicine (AOM) through professional examinations and certification of individual practitioners.

Accreditation Commission for Acupuncture and Oriental Medicine (ACAOM)

A private agency recognized by the U.S. Department of Education, ACAOM accredits professional, graduate-level education programs in acupuncture and Oriental medicine.

Pain Relief...continued from page 9

“superior” results from acupuncture treatments for the four types of chronic pain investigated: back and neck pain, osteoarthritis, chronic headache and shoulder pain. According to the authors, “Our results from individual patient data meta-analyses of nearly 18,000 randomized patients in high-quality RCTs [randomized controlled trials] provide the most robust evidence to date that acupuncture is a reasonable referral option for patients with chronic pain.”

Jim Pastore, M.Ac., L.Ac., is a Washington, DC area writer and acupuncturist practicing at The Mindfulness Center in Bethesda, MD. He teaches in the Master of Acupuncture program at the Tai Sophia Institute for the Healing Arts, in Laurel, MD.

Certificate Program in Mediation in Health Care

By Sarah Aoanan

When I saw that HAP and the Center for Continuing Education at Sarah Lawrence were hosting a training session in Health Care Mediation with Westchester/Rockland Mediation Centers (WMC), I jumped at the opportunity. Mediation has interested me since the 6th grade, when my teacher told me I was a good mediator. The certificate program allowed me to pursue mediation skills on a professional level.

The program lasted from nine to five on Friday and Saturday, two weekends in a row. The sessions were well worth it, albeit exhausting. We didn't just learn about mediation as it is applicable in health care; I feel I gained skills applicable to all life circumstances. Mediation, as explained by Tajae Gaynor, one of the mediators at WMC, is a process that allows parties an opportunity to discuss issues that have led them to the point of contention. The mediator's role is to facilitate the discussion by asking questions, reflecting feelings and restating the information parties share to bring about collaborative negotiation. The end goal is for both parties to reach an agreement that is satisfactory to each of them.

The session began with a “Game of Life” which explored the competitive nature of conflict. The game introduced the differences between negotiation, mediation and arbitration. The three exist in order on a scale from avoidance to war: negotiation is a consensual dispute resolution process that does not involve a third party; mediation is a voluntary process in which a third party helps with communication and negotiation; arbitration is a process in which the disputing parties choose the arbitrator, who imposes a decision based on the information presented.

Tips for information gathering, in the hopes of highlighting issues, included identifying each party's positions, feelings and values. The issue is neutral; the positions are the demands of each party regard-

ing the issue; the values or interests are the needs of each party. We practiced these skills through role-plays, exploring how preconceptions and bias can impact mediation, collaboration and negotiation.

We learned that in a successful mediation, each party should be able to abide by the mutually agreed upon solution. Mediators are impartial third party entities who empower those involved to resolve their issues in mutually beneficial ways. With the assistance of a mediator, parties identify issues, clarify perceptions and explore options for mutually acceptable resolutions. Mediators are not meant to solve the issues; their role is to bring them to light in a neutral voice and guide the negotiation. Jenny Besch, the director of the program, quoted Lee Hamilton in repeating that, as mediators, “Our end is their beginning.” The parties involved are the ultimate decisionmakers in mediation and it is for them to take from it what they will.

Mediation in health care can aid emotional healing and improve patient care. In lawsuits, mediation of medical malpractice provides savings for the parties by shortening the litigation process and arriving at an agreement without a trial. Attorneys and hospitals understand the financial savings that often accompany quick resolution through mediation. But there is also potential for mediation to repair damaged therapeutic relationships, improve customer satisfaction and provide information that enhances patient safety within provider organizations.

The training was not just a certificate program for career enhancement but, in my opinion, also an opportunity for life skills enhancement. It taught me how to listen for concerns, needs and wants without forcing my own opinions as to proper resolution of the issues. We addressed topics such as culture, perceptions, bias, prejudice, discrimination and verbal and non-verbal communication. Through role-playing, we were encouraged to develop empathy and shift our perspectives. Understanding each party's point of view allowed for facilitation and resolution of disputes.

Sarah Aoanan is a graduate student in the Health Advocacy Program.

Healthcare Advocacy Conference: Leading Edge of Reform

After much deliberation and concern for those affected by Hurricane Sandy, the National Association of Healthcare Advocacy Consultants (NAHAC) decided to proceed with their fourth annual conference for the vast majority of registrants who could make it to Boston. The conference provided stimulating professional education for those with a private practice as well as those who work as consumer advocates and policymakers. The sessions included topics specific to direct practice with individuals—navigating health insurance problems, new frontiers in cancer research, working with aging parents—as well as talks on changes to the health care system—reinventing primary care, the impact of health care reform, the patient-centered medical home. For further information visit the NAHAC website: <http://www.nahac.com>

Internship at Pulse...continued from page 8

cine and care; it is not one perspective or one narrative that has to dominate everywhere. The stories in *Pulse* have inspired me and it is these individual voices that inform the larger world around me.

Please know that *Pulse* is partially supported by the Department of Family and Social Medicine at Albert Einstein College of Medicine/Montefiore Medical Center in the Bronx, New York, and does not share *Pulse* subscriber email addresses. Since the goal of *Pulse* is to generate a dialogue that is open and free from bias, advertising from companies that have vested financial interests in health care is neither sought nor accepted.

Debra Finkelstein is a graduate student in the Health Advocacy Program.