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Letter from the Director

By Laura Weil

On the health care legislation front, everything seemed overshadowed by the almost astonishing passage of the federal health care reform bill. The eventual effects of this ground-breaking event will mostly play out over the next few years, and the Health Advocacy Bulletin will reflect on the coming changes from an advocacy perspective as the process of implementation unfolds.

One area, though, that will definitely have to be watched closely is the continuing and expanded ban on federal funds for abortion coverage. President Obama reaffirmed the Hyde Amendment this year, which prohibits the expenditure of federal funds on abortion except in a narrow set of circumstances involving rape, incest or danger to the life of the pregnant woman. This impacts no small segment of the population. It includes Medicaid recipients — low income families with children, pregnant women and individuals with disabilities — and also the less broadly recognized group of women in federal prisons, the armed forces or the Peace Corps and Native American women who receive their care through Indian Health Services. Health reform legislation threatens to expand that restriction to any woman covered by a plan that receives any federal subsidies. This could have a significant and devastating effect on women's reproductive rights. Health advocates must take notice.

On a more local level, and with more immediate impact, another new law has gently slipped into place. On March 16, 2010, New York State Governor Patterson signed into law the Family Health Care Decisions Act, allowing New Yorkers to make decisions about medical treatments for their loved ones. Until now, New Yorkers who had not designated a health care decision maker in a Health Care Proxy or other advance directive were at the mercy of hospital policy and physician bias if they became incapacitated and were unable to communicate their preferences about end of life decisions.

Assemblyman Richard N. Gottfried, Chair of the Assembly Health Committee, said, "It has taken 17 years of tortuous struggle to get to this day. Now, families will be able to make medical decisions for loved ones who don't have the ability to do so. Patients will no longer be denied appropriate treatment, subjected to burdensome treatments, or have their wishes, values, or religious beliefs violated."

The Act truly represents a sea change for health care decision making in New York. Until now, the default position regarding treatment has been "full out everything" and common law provided an often insurmountable barrier for requests to withhold or withdraw life-sustaining treatment from loved ones, absent specific instructions from the patient in the form of "clear and convincing evidence." Given that a minority of people have taken the time to execute advance directives, this left most patients and their family

members caught in a surreal nightmare of unwanted, usually painful, frequently futile interventions when a more sensible, humane and appropriate course would lead toward symptom management and maximizing dignity at the end of life.

"The [Family Health Care Decisions] Act truly represents a sea change for health care decision making in New York."

This is a sentinel event for rationalizing the costs of health care in the United States. According to Zhanglf Baohui (*Archives of Internal Medicine*, Vol. 169, No. 5, March 9, 2009), higher health care costs in the last week of life are associated with worse quality of death. Given that 30% of Medicare dollars are spent in the last year of life, think what savings of human suffering as well as health care dollars can be realized by simply allowing patients' loved ones to assure that wishes about end of life are honored. It's one of those rare examples of concordance between the best interests of society, the individual and the balance sheet.

At last New York has joined the ranks of states that recognize the rights of patients to have loved ones with knowledge of their personal values, preferences, and beliefs make decisions for them. That's a better scenario than having those decisions made by well-meaning but uninformed providers who just don't know better than to "do everything" or by those who stand to benefit from the fee-for-service payment structure that rewards that behavior.

Now, of course, a change in physician practice and hospital culture is required. We need to move forward from the acculturated habits of physicians who have not been trained to recognize the legitimacy of palliative care as a valid treatment option. We need to address reimbursement structures so that palliative care and hospice care are accessible — with sufficient numbers of qualified clinicians and appropriate insurance participation. We need to make the possibility of a good death the norm, rather than the exception. This is fertile ground for advocates — on the ground as well as at the health policy level.

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Letter from the Editor

By Barbara Robb

Taking advocacy out of the classroom and into the community — that's how I would describe the theme of this issue of the *Bulletin*. Rebecca Johnson first met members of Mossville Environmental Action Now (MEAN), a grassroots environmental justice organization, in 2006. She became more involved with the group this past year, then brought health advocacy graduate students into the picture as well. Eight students have spent a

considerable amount of time, including their spring break, working with MEAN. Take a look at their blogs to see photos and read their day-to-day descriptions of working in Mossville. We'll include a more formal report about the project in the next issue of the *Bulletin*.

To read Rebecca Johnson's blog, see <http://urbanecology.blogspot.com>. To read students' blogs, see <http://mossvilledispatches.blogspot.com>.

We've featured MEAN in this issue, with articles by Rebecca Johnson and four of the

health advocacy students. We've also included articles by two HAP graduates. Megan Donovan writes about her work with the American Heart Association's Healthy Families, Healthy Kids campaign in Pennsylvania. Helen Hovdesven describes her work as Co-Chair of the Patient and Family Advisory Council at the newly established Johns Hopkins Memory and Alzheimer's Treatment Center in Baltimore.

Autism Series at Sarah Lawrence College

The Health, Science & Society Group and The Child Development Institute are hosting a series of discussions about autism.

The initial event on March 2nd focused on genetic, social and environmental factors in autism. **Peter Bearman**, Director of the Lazarsfeld Center for the Social Sciences and professor of social science at Columbia University, discussed his work investigating social determinants of the autism epidemic.

On April 19th **Trevor Pinch**, Professor of Science & Technology Studies and Sociology at Cornell University, will speak about autism and vaccine controversies. His talk on Expertise, Parenting and Risk will explore the issues both from a science studies perspective and as a parent who has made decisions about vaccination while grappling with medical uncertainty.

Temple Grandin is scheduled to speak at the third event on September 23rd. Grandin is a Professor of Animal Science at Colorado State University and a consultant to the livestock industry on animal behavior; she is well known for her advocacy efforts in the field of autism. She will offer a personal look at the sensory and cognitive experience of autism.

The fourth event, planned for November, will focus on treatment, with a panel discussion of various therapeutic and educational measures that have been used to assist children with autism.

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. Feel free to send anything that's happened to you in the last couple of years. Shawna can be reached at shawna.irish@gmail.com

Health Advocacy in Action: Student Work in Louisiana

I Know Some Folks Who Can Help With That... How HAP Met MEAN

By Rebecca O. Johnson

By the time you read this article you may have already seen the CNN special, "Overexposed," which focuses on the struggles of the people of Mossville, LA for their health, their land and their lives in the midst of the pollution emanating from chemical and oil refineries that dominate the landscape and economy of Calcasieu Parish, Mossville's home county.

I first met Mossville Environmental Action Now (MEAN), the grassroots environmental justice organization formed by the people of Mossville, a year after Hurricanes Katrina and Rita. I was a circuit-riding technical assistance provider helping the Gulf Coast Fund build the capacity of the organizations they had helped grow out of the degradation that was our country's response to that catastrophe. I knew then that I would work with them in any capacity they needed me, whenever that became possible.

"I first met Mossville Environmental Action Now (MEAN)...a year after Hurricanes Katrina and Rita."

In the past year I have had the good fortune to provide additional organizational and fund development assistance to MEAN through a grant from the Gulf Coast Fund and the Environmental Support Center. During one of my visits, as we were thinking about organizing goals for the coming year, community participants decided they needed a free clinic, one that would address the enormous body burden that comes with living with so much air and groundwater pollution as well as provide firsthand epidemiological evidence of the very real consequences of ignoring strict environmental regulation of the oil and chemical industries.

As they discussed and settled on the free clinic I told the MEAN leaders and members, "I know some folks who can help with that." Those folks are eight graduate students in the Health Advocacy Program. Gloria Escobar-Chaparro and Margaret Rubick are participating for their capstone projects; Toi Scott, Rebecca

Hudson, Nicole Zolofra and Elizabeth Givens are doing fieldwork projects; and Joshua Lapps and Ashley Gephart are participating as volunteers.

I hope the following articles by the HAP students participating in this important work are as inspiring to you as my work with them has been to me. We are about to go to Mossville during spring break. We'll report back the results of our work in a future issue of the HAP Bulletin.

Here is a bit of background on Mossville, MEAN, CONOCO/Phillips and environmental justice organizing:

Mossville was founded after the Civil War by free black people. Homes and land have been passed down from one generation to the next, but the town was never incorporated. The residents had no municipal decision-making power. The town was eventually split and annexed by Westlake and Sulphur. The state of Louisiana and its parishes (the equivalent of counties in other states) actively courted chemical producers, presenting Lake Charles as a convenient location for their factories — near the Mississippi River, the Gulf of Mexico and major rail transportation. The result has been an environmental disaster.

This working class African-American community formed MEAN when they noticed unusual levels of jaundice, skin diseases, anemia and respiratory and endocrine disorders among residents. In 1998 and 1999 they took air samples to determine what chemicals were being emitted by the 20 largest polluters in Lake Charles. These industries, which include PPG, Louisiana Pigment, CITGO, Westlake Polymer, Firestone Synthetic Rubber and CONOCO Lake Charles Refining, helped make Calcasieu one of the most polluted parishes in a state that the EPA ranks in the top 20 percent for health risks from air pollution.

MEAN's air quality testing, through a community-based investigative process known as Bucket Brigades (www.bucketbrigade.net), revealed dangerous levels of carcinogens, developmental toxins, neurotoxins and endocrine-disrupting chemicals. Manganese, n-hexane and toluene lead the list of 20 toxic chemicals released



A duet of emissions from Mossville refineries

in their parish. Blood tests showed the residents to have dioxin levels three times that of the general U.S. population. The community health survey revealed Mossville to be "a very sick community," in the words of Dr. Marvin Legator in his *Symptom Survey for the Community of Mossville*.

The Environmental Justice movement is comprised of generally grassroots organizations seeking to address the largely hidden or ignored effects of industrial, agricultural, mining and waste management pollution on low income and working class areas and communities of color. Organizing by the residents of Love Canal, a neighborhood near Niagara, NY that was built on a dumpsite used by the Hooker Chemical Company, was the first widely recognized environmental justice effort. During their four-year campaign in the 1970s to protect themselves and their children from the effects of toxic levels of PCBs in the soil under their homes and schools, the members of the Love Canal Homeowners' Association had a standoff with federal agents that could be described as a kidnapping. Since then, communities all over the country have forced local, state and federal government to clean up toxic sites, won medical settlements and forced polluting industries to relocate and remunerate residents for their losses. But "Cancer Alleys," as these areas of unusually and disturbingly high rates of cancer are called, still exist in Ohio, New Jersey

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and Louisiana. As noted in *Breathing Poison: The Toxic Costs of Industries in Calcasieu Parish, Louisiana* (MEAN, Lake Charles Area Concerned Citizens, 1996-99), "Poor health and environmental contamination jeopardize the survival of communities like Mossville."

Today, MEAN is targeting CONOCO for its refusal to control the toxic effluent pouring from its stacks. It refines 239,000 barrels of high sulphur crude oil each day, on property abutting the historic Mossville community. This past spring MEAN conducted another community health survey and found residents' health to have worsened since surveys were conducted in 1998 and 2001. A Health Fair was held at the end of August where Mark Mitchell, MD, MPH, from the Connecticut Coalition for Environmental Justice and physicians from Houston and Morgan State University further evaluated the impact of these toxic industries on residents' health while offering basic screening for conditions such as high blood pressure and diabetes.



MEAN officers Mrs. Dorothy Felix and Mr. Mouton with two youths from the community, at MEAN's Family Fun Day.

The members of MEAN, and environmental justice organizations throughout the country, are struggling against incredible odds, not least of which is that community members frequently work in the industry that is poisoning them. And those same industries provide charitable contributions for all manner of

social, recreational and municipal services. These realities bring enormous pressure on grassroots activists — do not confront the employer, do not make waves with the company that may be a town's largest donor.

Of course, the biggest problem for these groups is us, our economy and the ubiquity of and necessity for the products these toxic industries manufacture. Will you give up paint for your home, specialized glass for your car windshield, tires for your car? It becomes our responsibility to respond to the demands of organizations like MEAN, examine our own consumption habits and support their organizing efforts. It's the least we can do for the people who are being poisoned for our lifestyle.

Rebecca O. Johnson is Executive Director, Cooperative Economics for Women and Adjunct Faculty, Boston College Graduate School of Education. She teaches The History of Health Care in the Health Advocacy Program.

An Internship Experience with Grassroots Activism

By Margaret Rubick

I began my second internship, Mossville Environmental Action Now (MEAN) 2010, not knowing that it would turn into a project that looks likely to fill 1000 hours and become a capstone, nor that it would occupy my thinking day and night for weeks at a time. I signed up because grassroots activism is outside of my comfort zone and it promised to be a learning experience. It would bring new vocabulary, new models, new methods and on-the-road experience in a world I did not know, encountering environmental racism in a small unincorporated town in Southwest Louisiana. Of course I said yes. My first task was to begin reading for a literature review. Minkler and Wallerstein's book, *Community-Based*

"I signed up because grassroots activism is outside of my comfort zone."

Participatory Research, proved to be a great introduction to the southern (meaning south of the equator) approach to engaging people in community to save themselves. Of course one book is never enough, so I moved on to Freire's *Pedagogy of the Oppressed* and dipped into bell hook's *killing rage* to hear a black woman's perspective of stereotypes of whites. My team members, Toi Scott and Nicole Zolofra, read with me. Nicole read Barbara Israel's *Methods in Community-Based Participatory Research for Health*, while Toi concentrated on researching organizations, including the government agencies that recognize this approach. All the reading reinforces that community-based participatory research is recognized both in academia and in practice.

Practice is the operative word here. My team and I practice contacting each other, asking questions, providing feedback. The tasks we perform are changing constantly — the model calls for us to co-create something that is alive. The literature review was only a beginning. We now work together to look at the next

portion of our work. Nicole will focus on children's activities. Ashley Gephart, who graduates in May, is jumping in to bring her experience with children to our Family Fun Day, while Toi assists the community with a website. I will focus on scheduling and coordination activities. We get on and off the metaphorical bus

"Our mission is not to fly in with a silver bullet; it is to listen, assuming that the collective wisdom of the community can best identify needs and solutions."

to take care of details and then move on to the next step. We all multitask, taking on more activities, handing off the baton when we need to. In a week, we will all be in Mossville together. We will jointly conduct a health needs interview and there will be new energy to take to the next set of activities...iteratively acting, listening, reflecting, changing, moving forward.

An Internship Experience with Grassroots Activism

When I traveled to Mossville for the first time, I went with my co-team leader, Gloria Escobar, and our field supervisor, Rebecca Johnson. Our flight took us from New York to New Orleans. I visited the downtown office of an environmental justice movement, listened to the fundraising efforts of a former Mossville resident and toured the Ninth Ward, which still bears the scars of Katrina's rage from five years ago. Coding on doors by public health searchers is a reminder and sometimes a token/souvenir/memorial of the searching of properties for living and dead. Some houses have been restored, others sit jacked up on stone; still others are boarded up. Water standing for months provides fertile ground for unimaginable mold...it is hard to believe that more buildings haven't been razed to eliminate toxicity.

Toxicity. Now I cannot delay talking about Mossville any longer. Toxicity and a place called Mossville sound like a contradiction in terms, but the fertile ground and clear water with abundant fish discovered by African-Americans in the 1790s are long gone. The fish have been inedible for many years now; it is not advisable to drink the water, let alone swim in it. Residents wash and cook with bottled water and spend their days wondering just when the next chemical accident will occur. It is difficult to imagine so many plants in one area. It is even more difficult to remember that the fourteen petrochemical plants that border Mossville are but a small part of a larger industrial area. They are part of the 136 chemical plants that occupy an 85-mile stretch of the Mississippi known as Cancer Alley. Flares burn day and night; smoke pours out 24 hours a day. Contaminated water runs south; the toxic fumes follow whichever direction the wind blows.

"Sarah Lawrence students will partner with townspeople."

Someone asks if the residents have complained to the government for help. The answer is yes: they have appealed to the Environmental Protection Agency (EPA), the Agency for Toxic Substances and Disease Registry (ATSDR) and the Louisiana Department of Equal Justice. In 1999 residents traveled to Geneva to appear before the United Nations Commission on Human Rights. They are

pursuing a class-action lawsuit against one of the chemical companies. What is remarkable is that after more than twenty years (thirty for some), the townspeople have the energy to keep on fighting.

The people of Mossville have been advocating for clean air, water and soil for decades. Federal agencies acknowledged in the late 90s that dioxin levels were precipitously high, only to "lose" the results. Hurricanes have destroyed records of air samples. Promises have been made and not kept.



Shirley Johnson's tap water

Our mission is not to fly in with a silver bullet; it is to listen, assuming that the collective wisdom of the community can best identify needs and solutions. Partnering with Sarah Lawrence gives MEAN access to an Institutional Review Board to protect their rights in research, and volunteer students to assist with documenting needs and plans. In March we will conduct a door-to-door campaign, inviting residents to participate in an interview, making it a random sample to ensure validity. Studies in the past have resulted in anecdotal evidence and have been shot down by ATSDR.

This effort is being led by HAP Professor Rebecca Johnson and I am one of two team leaders who have now met twice with members of MEAN, which has requested help with starting up a free clinic and possible relocation of townspeople. Not everyone wants to move — this has been home to some families for more than two centuries. The Felix family

has five generations currently living in this unincorporated township, where tumors grow in sinuses and breathing is labored for everyone. Mossville is smaller than it once was; petrochemical companies have steadily encroached on the land. Conoco bought out some residences in the early years of this decade, only to expand its plant. Mossville was featured in a 2002 documentary called "Blue Vinyl." I recognized several faces on the screen as I watched the film, faces of those who are still alive and still living in Mossville.

When we return to Mossville in March, we will be there as a team of nine people. Sarah Lawrence students will partner with townspeople to conduct interviews, host a family day and an open house. We will plan next steps, clarify goals and set priorities. Mossville brings the voice needed to determine the path forward. We will all learn and we hope the experience will prove useful to residents.

So this internship is a learning experience on many different levels. It is my first face-to-face encounter with environmental racism. It is my introduction to the brave and faith-filled residents. Mr. Bennett took us on a driving tour down "the escape route," a pothole-filled dirt road that runs parallel to the railroad tracks, which are lined with cars full of chemicals. He and other guides showed us the house that burned with Mr. Prince inside; when the fire trucks arrived, the hoses were too short to reach his house. They also showed us the "rec center" where the community holds meetings. We met in one of the many churches that serve the population. Meetings often begin and end with prayer. It is well documented that people who have some religious or spiritual faith cope better with terminal illness. I find that although I am not Christian, if they pray I say "Amen." I'll take all the help we can get. It is my sincere hope that I can be of service.

Margaret Rubick is a graduate student in the Health Advocacy Program.

Collaborating with Local Activists for Environmental Justice

By Gloria Escobar-Chaparro

One of the most important lessons I've learned from working with Mossville Environmental Action Now (MEAN) is how very far we are from the realization of the dream of equality and justice in America. As a society we may no longer tolerate police brutality and lynchings but we somehow tolerate the slow poisoning of entire communities, particularly if the residents are black and poor. This is what is happening in Mossville.

Much of MEAN's effort has been focused on the legal arena, filing petitions and lawsuits to force the petrochemical industries to relocate the residents to an area with a more healthful environment. However, MEAN has also realized that the health of the community is at risk because of the lack of access to affordable health care.

Unemployment in Mossville is high, but even among the employed, many residents have inadequate or no health insurance. The petrochemical industry supports health clinics with sliding payment scales, but you must have a job in order to qualify for services. MEAN determined that one goal of the collaboration with Sarah Lawrence College should be the creation of an environmental scan and an operational plan that would support the effort to establish a free health clinic.

"...we somehow tolerate the slow poisoning of entire communities, particularly if the residents are black and poor."

Under the tireless direction of Rebecca Johnson, there are eight students actively involved in the Mossville project. Margaret Rubick and I are team leaders; four other students (Liz Givens, Beja Hudson, Toi Scott, and Nicole Zolofra) are using this project as fieldwork placements. Joshua Lapps and Ashley Gephart are helping out as well. The focus of my team, which consists of Beja, Liz and Josh, is creation of the environmental scan and free clinic operational plan.

An environmental scan (ES) is an organizational and strategic planning document designed to help organizations gain

a comprehensive understanding of the environment in which they are operating. Completion of the ES required the team to conduct in-depth research on topics such as political figures, clinical and medical resources, persons trained in medical fields, and the location of churches, schools, and community centers. The information we provided far exceeded anything the community had available previously. MEAN realized that they could utilize the ES for a wide range of purposes, such as networking with churches and congregations, identifying potential sources of funding and grants and locating new health care providers to consider. We have also stressed that this information belongs to them, and they can use it and control it as they see fit. It has taken some time for MEAN to believe that SLC students were actually conducting research to bring to the community, rather than to take information from them for our own purposes.

Each time I have traveled to Mossville I have been struck by how wary the community is of academia and outsiders. This mistrust is the justified result of repeated deceptions by others, but we should all be cognizant of the fact that we must continually work to earn and maintain the community's trust.

The operational plan will provide a detailed and specific roadmap of what is needed in order for members of the community to run a free health clinic without involvement or funding from the petrochemical industry. The services offered will be determined by the community and may include basic preventive health care as well as toxicology testing to help build an accurate and scientifically valid database of information on the levels of toxins in the residents' bodies, which can then be correlated to the rising incidence of disease and sickness in the community.

This capstone project has been much more challenging and educational than my prior internships. Learning completely new skills (how to create an environmental scan and operational plan, write an Institutional Review Board application, among other things) and gaining knowledge in new fields (community-based participatory research, environmental justice, undoing racism) in a very short timeframe was simultaneously challenging, exciting and terrifying. My time

in Mossville was incredibly enlightening and opened my eyes to the shameful and inexcusable existence of institutionalized racism in America. How else could I interpret government reports which state that residents have up to one hundred times the safe levels of dioxins and toxins in their bodies and acknowledge that the local industries are emitting these exact poisons, but conclude that sources of the toxins can't be identified?

"I have been struck by how wary the community is of academia and outsiders."

Our capstone project is intended to be a culminating experience and achievement of all we have learned in the Health Advocacy Program. However, I view my work in Mossville, with MEAN and with the SLC faculty, not as a capstone but rather as a cornerstone, a foundational rock upon which I hope to build my future in health advocacy.

Gloria Escobar-Chaparro is a graduate student in the Health Advocacy Program.

To access the CNN story on Mossville and a video of Dr. Sanjay Gupta's visit to the community, use the following link: <http://www.cnn.com/2010/HEALTH/02/26/toxic.town.mossville.epa/index.html?hpt=C1>

Developing Anti-Racist Ethics

By Toi Scott and Joshua Lapps

Across the nation there is a growing sense of awareness about a different, albeit not novel, kind of oppression. It particularly targets specific members of race and class and significantly impacts entire towns and cities. "Environmental Racism" is a somewhat newly coined term that addresses the discriminatory practice of marginalization of minority communities through lax health and corporate regulations and systems that end up poisoning the residents and the earth. People with lower income have neither the power and resources to defend themselves against industry giants who pollute their air and water supply, nor the access to adequate health resources to improve their health. Community members' pleas go unheard as the government proves to be unwilling or unable to address the atrocities happening in their backyard. Very few actions are taken and dialogue seems ineffective, at best. Actions would admit fault, something a system valuing corporate interest would be loath to do. While thousands are affected by particulates and plumes, the government and oil and chemical industries continue to toss around a political hot potato as residents of these communities get sicker and die. The victims in environmentally-affected communities only care to know who will create the solution. This is where environmental justice groups come in and where our fieldwork with MEAN begins.

"As health advocates it is imperative that we help marginalized communities find their voice."

As health advocates it is imperative that we help marginalized communities find their voice. As such, we work with community members to give them the resources to do and speak for themselves. A mixed team of first- and second-year HAP students has been honored with the opportunity to contribute to the empowerment of a Louisiana community faced with devastating environmental degradation and monumental health concerns. We are partnering with the community to do research, fund development, perform a health needs assessment and aid in beginning a health clinic. The aim is not to come into the community as outsiders with ideas and goals that are very disconnected and different from the com-

munity, but to share knowledge and resources with the residents of the community. We hope to form a collaboration in which all those with specific knowledge or expertise can support each other in working toward the same goal.

In order to be the best advocates, we first need to look inside ourselves for all of our biases and privileges that may challenge our work or prevent us from understanding the connection between structural racism, the environment and health. Indeed, as Marcel Proust stated so eloquently, "the real voyage of discovery consists not in seeking new landscapes, but in having new eyes." To gain this new lens, students participating in the fieldwork were asked to attend an Undoing Racism workshop sponsored by the People's Institute for Survival and Beyond. Ultimately, the message is clear — that racism continues to thrive in systems, regulations, behaviors and practices throughout the country. The People's Institute is a network of anti-racist organizers and educators founded in 1980 that seeks to unmask the causes of racism and oppression and create ways to dismantle these systems.

Through reflection, dialogue and education, the Undoing Racism workshop challenged us to critically examine the underpinnings of society with an anti-racist frame. Much of the current success in society is due, directly or indirectly, to oppressive and discriminatory systems that allowed one person to benefit by taking advantage of another. Another key facet of the program is an emphasis on exploring the notions of internalized racial inferiority and internalized racial superiority — the conscious and subconscious ways in which we replay and believe the roles and disem-

powerment/empowerment set forth by society. The awareness gained from these insights sets the stage for anti-racist activism and organizing.

"We are both witnesses of, and advocates for, the community during our fieldwork."

Our attendance at the workshop is core to understanding the complex issues that have contributed to the situation in Louisiana. We are both witnesses of, and advocates for, the community during our fieldwork. Unless we have an understanding of the complex layers and constructs contributing to the oppression of the nearly invisible citizens of Louisiana, we may not be able to fully assist the community. Knowledge and consciousness about the etiology of marginalization and disenfranchisement is the first step towards a solution.

The incorporation of an anti-racist ethic in advocacy work is vital to acting truly as advocates for all people. To do so exposes the systems that we may otherwise be in favor of — social services, legal systems, for example — as fundamental players in oppression for people and communities. With this recognition, we can work to pull apart racism and create equitable and just systems in its place. To do so means that we are not fighting just the symptoms of racism, but tackling the cause.

For more information about The People's Institute and its programs, please visit www.pisab.org.

Toi Scott and Joshua Lapps are graduate students in the Health Advocacy Program.

Faculty News

Rachel Grob, HAP faculty, Associate Dean of Graduate Studies and Director of the Child Development Institute, traveled to Dalhousie University in Halifax, Nova Scotia in March at the invitation of the Department of Bioethics. She was the featured speaker at the Bioethics Panel Series on Newborn Screening, where she spoke about Testing Baby: Parents' Perspectives on Expanded Newborn Screening. She was joined by Mark Schlesinger from Yale University for a talk on Educating for Advocacy: Teaching Skills, Framing Aspirations, Sparking Engagement. The session highlighted key thematic elements embedded in advocacy education at Sarah Lawrence and key competencies suggested by a nascent U.S.-based Health Advocacy Association.

Reports from the Field

Healthy Families, Healthy Kids

By Megan Donovan

Long before First Lady Michelle Obama publicized the dangerous rise in childhood obesity by kicking off the national “Let’s Move” campaign, the Great Rivers affiliate of the American Heart Association (AHA) saw the pattern of unhealthy living and its consequences for children living in the Lehigh Valley. The metropolitan area of the Lehigh Valley is Pennsylvania’s third most-populous, and the impact of the high rate of childhood obesity is felt in area schools, health departments and families. To respond to the epidemic, the local AHA chapter applied to host a series called “Healthy Families, Healthy Kids,” which provides education and activities for families with children. This pilot program is the first of its kind for the AHA, and reflects the agency’s commitment “to help people achieve a heart-healthy lifestyle.”

The series includes four community-oriented programs intended to educate families and children on the risks of obesity while demonstrating healthy food options, child-oriented fitness and healthy-living activities for the whole family. At a recent event at a local mall, the AHA put together a “scavenger hunt” that encouraged over 300 area

kids to go from station to station in the mall to learn how to make healthy snacks, participate in Wii Olympics, and get their heart rates up by playing with hula hoops and jump ropes. A regional marathon in April provides the opportunity to host a kid’s race complete with information on heart health and other activities. A “training camp” at the area’s triple-A baseball stadium in August will provide a platform for additional outreach while kids run the bases and practice other fitness activities with local celebrities. The series will continue to be developed as it shows success in combating the dangerous epidemic of obesity in the Lehigh Valley.

“...the impact of the high rate of childhood obesity is felt in area schools, health departments and families.”

My involvement with this series came after working on the child health and nutrition issue during my capstone project with Pennsylvania’s Allentown School District (ASD) on a Strategic Plan for the Child Nutrition Services department. Through the knowledge required to complete the project, I became well versed in the topic of child-

hood obesity in the region. In doing research and field work for the Strategic Plan, I had the opportunity along the way to meet key players committed to healthy environments and healthy children. As a result of the knowledge I had gained during my capstone project, as well as the enthusiasm I demonstrated in the effort, I was asked to be a part of the “Healthy Families, Healthy Kids” planning committee. I serve on the committee as a volunteer, and feel fortunate to have gained the field experience and contacts that the opportunity has provided. In this role I’ve attended committee meetings, helped plan and organize events, sought donations and support from area organizations, and networked with local leaders to bring individuals and organizations together to work on this valuable collaborative effort. As the series continues in conjunction with the discourse that has followed announcement of the “Let’s Move” campaign, the AHA will be at the forefront of the conversation of children’s heart health in the Lehigh Valley.

Megan Donovan is a graduate of the Health Advocacy Program.



Hula hoops at the mall event

Health Advocacy Never Ends!

By Helen Hovdesven

You can pick up a magazine or newspaper almost daily and read about dementia in the sports section or on the front page. According to the September 2009 World Alzheimer’s Report, “The dementia epidemic is upon us. There are an estimated 35.6 million people with dementia. The numbers are expected to nearly double every 20 years to 65.7 million in 2030 and 115.4 million in 2050. It is one of the most disabling of all chronic non-communicable diseases.”

Alzheimer’s disease is the most common form of dementia in older individuals, but not all dementias are caused by Alzheimer’s. Stroke, other vascular disorders, brain tumors, head injury, Parkinson’s disease, Huntington’s and a variety of other disorders can also cause dementia. The term refers to symptoms caused by disorders that affect the brain. Memory loss is a prominent symptom; others can include disorientation in time and place, difficulty with language, mood and personality changes, inappropriate behavior and impaired coordination (www.nlm.nih.gov/medlineplus/dementia.html).

There isn’t any one test for Alzheimer’s diagnosis. Instead, investigation focuses on ruling out other possible causes of the dementia symptoms. Definitive diagnosis of Alzheimer’s can be made only by examination of brain tissue after the patient’s death. Before that, the diagnosis is phrased as possible or probable Alzheimer’s disease.

My husband, Arne, was diagnosed with Alzheimer’s disease in early 2001. It was in January 2002 that our journey took us to Johns Hopkins Hospital in Baltimore, through a referral to Constantine Lyketsos, MD. In spite of the devastating diagnosis, Hopkins made our journey, with their plan of care and support for each of us, as good as could be.

As a student in the Health Advocacy Program in the early 90s, I had the privilege and opportunity of working as a Patient Representative with Paula Lestz (also a HAP graduate), Director of Patient Relations at the Westchester County Medical Center. After Paula’s death, I was appointed Acting Director until my retirement in 1995. My husband’s illness led to my involvement at Hopkins.

As a HAP student, my assigned paper topics were Alzheimer’s Disease in Physiology and Life Care Communities/Continuing Care Communities in Health Law. Was that a coincidence? The Health Advocacy Program and my professional experience were a

tremendous help when my husband’s illness was diagnosed. I quickly became an authority on a subject even the well-intentioned and well-educated tend to avoid. Keeping a fearful distance wasn’t an option for me.

Along the way, the staff at Hopkins recognized that I could help others. For that, I credit in great part my HAP training. I now find myself with a great passion for working with Alzheimer’s patients and their families. Hopkins has been a learning adventure for me. Imagine retiring and having this wonderful opportunity to continue using my advocacy skills.

“The Health Advocacy Program and my professional experience were a tremendous help when my husband’s illness was diagnosed.”

I now find myself working alongside Dr. Lyketsos, Dr. Peter Rabins and others at Johns Hopkins. As Co-Chair of the Patient and Family Advisory Council (PFAC) at the newly established Johns Hopkins Memory and Alzheimer’s Treatment Center, our common goal is to bring patients, families and staff together to meet the needs of Hopkins patients and their families. The Center seeks to provide cutting edge treatments and innovative programs for patients with Alzheimer’s and to pioneer research studies. It is a collaborative partnership of the psychiatry, neurology and geriatric medicine departments at Hopkins. The Center also strives to promote collaborative partnerships with patients and families. The PFAC works to identify needs and concerns of patients and families, encourage their involvement and strengthen communications with physicians and staff.

Here’s a list of some of the things I’ve done:

- Serve as a Board Member on the Advisory Committee in the Department of Psychiatry and Behavioral Science; the Committee members advise the Department and also serve as ambassadors for Hopkins;
- Attend the annual Mood Disorders Research/Education Symposium;
- Participate as a panelist, focusing on the caregiver, at the 15th Annual Conference on Alzheimer’s and Other Related Dementias;
- Attend a 3-day Patient and Family Centered Care Conference in Philadelphia, presented by the Institute for Family-Centered Care, which would help in developing the Hopkins PFAC;

- Assist in developing the Brain Donation Autopsy Brochure (brains are needed for research, as well as to confirm the diagnosis of Alzheimer’s);
- Participate in the Journey to Hope, Dr. Lyketsos’ annual update on Alzheimer’s Disease, by networking with attendees at the meeting and as a speaker; and
- Tape a series of podcasts on my personal experience as a caregiver for a family member with Alzheimer’s, diagnosis to death; the podcasts are available on the Hopkins website (www.hopkinsmedicine.org/psychiatry/specialty_areas/neuropsychiatry/memory_center).

Most rewarding is my work with patients and families, some of whom I visit in their homes. (More than 7 out of 10 people with Alzheimer’s disease live at home.) Patients and families feel the support. There is an instant and unique bond among caregivers of dementia patients. Feelings rarely need to be explained. Words are not necessary.

Here are some of the things I’ve learned that can make a difference for patients and families:

Dementia can have a gradual onset that is not always apparent to all. Alzheimer’s, which is only one of the dementias, has several stages. An advocate working with families affected by dementia must recognize that there is no one way, no right or wrong way, to do things. While the disease may be the same, each patient is individually unique.

Behaviors are perhaps the most difficult concern to address. Learn to enter the patient’s world. Always treat the patient with dignity. Make allowances, show interest, avoid distractions. Keep things simple. Don’t interrupt the patient and don’t raise your voice. Take one day at a time, and don’t look too far ahead. Help the family build a support system. Encourage family members to continue socializing. Most important, encourage and enable the caregiver to get professional help if needed.

Remind the family: Enjoy every moment with your family member — you’ll never regret it. The patient may not know you by your given name or relationship, but be assured that you are still in the memory bank. You are not forgotten!

Arne Hovdesven died in March 2009.

Helen Hovdesven is a graduate of the Health Advocacy Program.

HAP Holiday Party

HAP students, faculty and alumnae at the annual Holiday Party at 45 Wrexham.



HAP Director Laura Weil, Sarah Lawrence President Karen Lawrence and HAP Faculty Member Mary Ann Baily



Susan Guma, Dean of Graduate Studies, with HAP alumnae Diane Neff and Helen Hovdesven



Rachel Grob, Associate Dean of Graduate Studies and HAP Faculty (center) with HAP student Joshua Lapps and HAP alumna Helen Hovdesven



HAP Faculty Alice Herb (left) and HAP alumna Lois Steinberg

Upcoming Events

Thursday, May 6 6:00-8:00 P.M.

New York Academy of Medicine,
1216 Fifth Ave. at 103rd St., New York

Changing Concepts of Disease and Prevention from the Late Middle Ages through the Enlightenment

Speaker Miriam Mandelbaum, Curator of Rare Books and Manuscripts, will utilize material from the Library's collections dating from as early as the 14th century to illustrate her talk. This is the second event in the series Prevention: The Key to Urban Health. To register, call 212-822-7209 or go to www.nyam.org/events.

Friday, May 7

Metropolitan Hospital, Draper Hall,
First Ave. and 99th St., New York

Supporting Patients and Families at the End-of-Life

First Annual John Corser Bioethics Symposium, presented by the New York City Health and Hospitals Corporation Metropolitan Hospital. For more information, contact william.sakolsky@nychhc.org.

Wednesday, May 12 6:00-7:30 P.M.

New York Academy of Medicine,
1216 Fifth Ave. at 103rd St., New York

Health Care Reform & Access to Coverage

Keynote speaker John McDonough, Joan H. Tisch Distinguished Fellow in Public Health at Hunter College, will provide an overview of proposed legislation as it relates to coverage. Other panelists include Troy Oechsner, New York State Deputy Superintendent of Health; Sara Horowitz, founder of Working Today-Freelancers Union; and David S. Abernathy, senior vice president of Emblem Health. To register, go to www.nyam.org/events.

Thursday, May 20 4:30-8:00 P.M.

New York Academy of Medicine,
1216 Fifth Ave. at 103rd St., New York

Research with Incapacitated Adults: Regulatory Challenges and Perspectives from New York State and Federal Policymakers

Presented by the New York Academy of Medicine and The Metropolitan Ethics Network. Speakers: Jerry A. Menikoff, MD, JD, Director of the Office for Human Research Protections, U.S. Department of Health and Human Services; David H. Strauss, MD, Director, Office of Human Subjects Research, Department of Psychiatry, College of Physicians and Surgeons, Columbia University; Beth E. Roxland, JD, M Bioethics, Executive Director, New York State Task Force on Life and the Law. To register, go to www.nyam.org/events.

Sunday, May 23 through Tuesday, May 25

Washington, D.C.

National Breast Cancer Coalition Fund: 2010 Advocacy Training Conference

It takes more than awareness to end breast cancer: take action! Peel back the pink to learn what is really happening in breast cancer today and look beyond the surface to understand where we still need to go. Get trained and feel empowered to have a meaningful role in finding a cause and a cure. For more information, see <http://Takeaction.stopbreastcancer.org>.

Wednesday, June 2 5:30-8:00 P.M.

Gotham Hall, New York

Feeling Good:

A Celebration to Benefit Public Health Solutions

Public Health Solutions hosts its annual event, featuring a gourmet green market buffet and the opportunity to mingle with leaders in the public health and healthcare industries. Proceeds from the event will benefit Public Health Solutions, which develops, implements and advocates solutions to prevent disease and improve community health. For more information, contact Wendy Kleinman at 212-687-3924 or benefit@healthsolutions.org.

Sunday, June 6 through Friday, June 11

The Kennedy Institute of Ethics
Georgetown University, Washington, D.C.

Intensive Bioethics Course:

Charging Your Bioethics Batteries

Designed to address challenging topics in health care ethics, introduce participants to the philosophical underpinnings of bioethics and current major topics in the field, and provide them with skills to define and describe approaches to bioethics in medical practice. For more information, go to <http://kennedyinstitute.georgetown.edu>.

Monday, June 14 6:00-9:00 P.M.

Manhattan Penthouse, 80 5th Ave., New York

FRIA Annual Spring Benefit

Reception and dinner honoring **Joan H. Marks**, Director of the Health Advocacy Program at Sarah Lawrence College 1980-1998. For more information, see <http://www.fria.org/about/news/events>.

Tuesday, June 22 6:00-8:00 P.M.

New York Academy of Medicine,
1216 Fifth Ave. at 103rd St., New York

The Importance of Care Coordination

Who will care for us as we age? How can we ensure that we and our loved ones are receiving the benefits that are critical to our health and well-being should illness strike? Patricia J. Volland, Director of the Social Work Leadership Institute and Sr. VP for Strategy and Business Development, will speak about her professional and personal experiences, as part of the series, Prevention: The Key to Urban Health. To register, call 212-822-7209 or go to www.nyam.org/events.

Tuesday, October 5 6:00-8:00 P.M.

New York Academy of Medicine,
1216 Fifth Ave. at 103rd St., New York

Promoting Health Education to Prevent Disease in New York City

NYAM is teaching people to live healthier lives by developing and delivering educational programs addressing issues from diet and exercise to strengthening self-esteem in schools and community-based organizations. Joanne De Simone Eichel, Director of the Office of School Health Programs, will talk about the impact of these health initiatives as part of the series, Prevention: The Key to Urban Health. To register, call 212-822-7209 or go to www.nyam.org/events.