Letter from the Director

By Laura Weil

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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 least 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 on this ban by changing Medicaid eligibility requirements.

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The MA in Health Advocacy Program is supported by: The Fund for Sarah Lawrence
By Barbara Robb
Letter from the Editor

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 work going on 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://urbasciology.blogspot.com. To read students' blogs, see http://mossvilleledpatch.es.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 Lazersfeld Center for the Social Sciences and professor of sociology at Columbia University, described his work investigating social determinants of the autism epidemic.

On April 19th Trevor Pitch, 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
The HEALTH ADVOCACY BULLETIN is a publication of the Health Advocacy Program at Sarah Lawrence College, One Mead Way, Bronxville, NY 10708.

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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

By Rebecca O. Johnson

By the time you read this article you 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 the catastrophic. 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 many and so toxic air pollution and below ground 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 Rutbck are participating for their capstone projects, Tui 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 experience of autism.

I know some folks who can help with that...

Student Work in Louisiana

By Rebecca O. Johnson

To read students' blogs, see http://mossvilleledpatch.es.blogspot.com. To read Rebecca Johnson's blog, see http://urbasciology.blogspot.com.

The Environmental Justice movement is comprised of generally grassroots organizations seeking to address the ways that 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 kidnaping. 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 disturbingly high rates of cancer are called, still exist in Ohio, New Jersey

Continued on page 4
I Know Some Folks Who Can Help With That...How HAP Met MEAN

Wallerstein’s book, I find that although I am sincere hope that I can be of service. I’ll take all the help we can get. It is my 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.

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 bring me to what looks like a film set, a town with hoses were too short to reach his house. They also showed us the “rec center” where the young people go. We met in one of the many churches that serve the population. Meetings often began with prayer. It is well doc-umented that people who have some reli-gious 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.

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One of the most important lessons I’ve learned from working with Moshville Environmental Action Now (MEAN) is how very far we are from realizing the equal rights and the 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 Moshville.

Much of MEAN’s effort has been focused on the legal arena, filing petitions and lawsuits to force the petrochemical industry to relocate the residents to an environment that they can control. 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 Moshville is high, but even among the employed, many residents have inadequate or no health insurance. The petrochemical industry supports the local industries are emitting these exact toxins, information we provided far exceeded the expectations. Our 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 Moshville I have been struck by how wary the community is of academia and outsiders. This mistrust is justified, resulting from deceptions by others, but we should all be cognizant of the fact that we must continue to work to earn and maintain the community’s trust.

The operational plan will provide a detailed and specific roadmap 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 complete- ly new skills (how to create an environmental scan and operational plan, write an Institutional Review Board application, and open 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.”

Collaborating with Local Activists for Environmental Justice

By Gloria Escobar-Chaparro

By Toi Scott and Joshua Lapps

A cross the nation there is a growing sense of awareness about a different, albeit not novel, kind of oppression. This oppression is somewhat tangential toward topics such as race, class, and significant- ly impacts entire towns and cities. “Environmental justice” is a newly coined term that addresses the dis- criminatory 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 nei- ther 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 mem- bers, whether they have a degree or not, prove 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 values, continuing to be the norm for the future. While thousands are affected by par- ticulars and plumes, the government and oil and gas industry lives around a political hot potato as residents of these communities get sicker and die. The victims of environmental injustice com- munities only care to know who will create the solution. This is where environmental justice begins to be defined and where our fieldwork with MEAN begins.

As health advocates it is imperative that we help marginalized communi- ties find their voice.

As health advocates it is imperative that we help marginalized communi- ties find their voice. Our attendance at the workshop is core to empow- erment/empowerment set forth by the People’s Institute and its programs, please visit www.piab.org. Toi Scott and Joshua Lapps are graduate stu- dents in the Health Advocacy Program.

To access the CNN story on Moshville and a video of Dr. Sanjay Gupta’s visit to the community, use the following link: http://www.cnn.com/2010/HEAL-TH/02/26/toxic.town.moshville.epa/index.html?itp=C1

Faculty News

Rachel Grob, HAP faculty, Associate Dean of Graduate Studies and Director of the Child Development Institute, traveled to Dalhousie University 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 MaryAnne Rice from Yale University for a talk on Teaching Skills, Framing Aspirations, Sparking Engagement. The session highlighted key thematic elements embedded in advocacy education at Sarah Lawrence and key competencies sug- gested by a nascent U.S.-based Health Advocacy Association.
Hula hoops at the mall event for the whole family. At a recent event at a local hospital, parents and children on the risks of obesity while engaging in healthy activities. The local chapter of the American Heart Association (AHA) 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, children’s health 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 jumping 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..."

By Megan Donovan

Megan Donovan is a graduate of the Health Advocacy Program. My involvement with this series came after working on the child health and nutrition issue during my capstone project with the Applied Studies Department (ASD) on a Strategic Plan for the Child Nutrition Services department. Through the ASD’s knowledge required to complete the project, I became well versed in the topic of childhood 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 have 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.

By Helen Horvath

Can you 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 35.5 million people with dementia. The numbers are expected to double every 20 years to 65.7 million in 2020 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.

There isn’t any one test for Alzheimer’s diagnosis, and investigation focuses on ruling out other possible causes of the dementia symptoms. Definitive diagnosis of Alzheimer’s requires post-mortem examination of brain tissue after the patient’s death. Before that, the diagnosis is phrased as possible or probable Alzheimer’s.

My husband, Arne, was diagnosed with Alzheimer’s disease in early 2001. It was in January 2002 that our family took us to Johns Hopkins Hospital in Baltimore, through a referral to Constantine Lyketsos, MD, PhD, and following 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 Advocate. I was a Partner 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 topic was “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 author 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, as I have been writing 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 Rabits 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 promote cutting edge treatments and innovative programs for patients with Alzheimer’s and to conduct 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 strives to identify needs and concerns of patients and families, encourage their involvement and strengthen communications with physicians and researchers.

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 care of patients 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...

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

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 96th 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. Rosland, 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 Steimann at 212-687-3954 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://kennedyinstute.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.