

HEALTH ADVOCACY BULLETIN

The Journal of the Health Advocacy Program at Sarah Lawrence College

VOLUME 13, NUMBER 1

FALL 2005

Letter from the Director

By Marsha Hurst

As you can undoubtedly tell from these brief but news-filled pages, the Health Advocacy Program has had an incredibly busy and productive and exciting year. It really began with the 25th Anniversary Conference held last January on "Advocates in Research," the Executive Summary of which forms the bulk of this *Bulletin*. The

Conference was extremely successful and very timely, connecting not only with growth in the area of advocacy—as witnessed by some of the new careers noted in our section on graduates—but with our application to the Ford Foundation, via the Council of Graduate Schools to develop a new program in Applied Research Ethics (see Rachel's article in this *Bulletin*). We are now planning our second annual conference, on

an equally timely and important subject: "Advocacy & Genetics: Arenas of Engagement" (see Save the Date announcement). More and more prospective students come to us with an interest in combining advocacy and genetics, if not by earning two degrees, then by taking courses that integrate the two fields.

By holding these conferences, Health Advocacy is bringing advocates together here at Sarah Lawrence College. But we are also bringing our experience and understanding about advocacy and educating advocates to others by presenting papers, and by being part of a new networking movement among advocates and educators of advocates. We have been particularly excited about and fulfilled by the discovery of new colleagues in the advocacy education area: JoAnne Earp and her assistant Elizabeth French at the School of Public Health, University of North Carolina in Chapel Hill, and Meg Gaines, at the Center for Patient Partnerships, University of Wisconsin Law School. Meg teaches patient advocacy in the classroom and the "clinic" to any interested graduate and professional student at the University; and JoAnne and colleagues are developing patient advocacy courses for public health graduate students at UNC. We will report more about the work of these colleagues, and about the ways in which patient and health advocates are connecting with each other for common purposes, in future *Bulletins*.

And now, I am about to close my door—and shut down my computer—for the winter break. Time to work on the book Sayantani and I are co-editing (see faculty news) and immerse myself again in the History of Healthcare course I love to teach. Please stay in touch. If you are an alum and would like to contribute to our Health Advocacy blog, *The Health Advocate* (www.healthadvocacyslc.blogspot.com), please let me know. And by all means tell us more about your work as patient and health advocates, and about what you would like to see in future issues of this *Bulletin*.

HEALTH ADVOCACY PROGRAM IN THE NEWS

The Health Advocacy Program was featured this past fall in many articles about patient and consumer concerns. The ongoing *New York Times* series "Being a Patient" began with an article by reporter Jan Hoffman featuring the patient journey of Meg Gaines, our friend and colleague at the University of Wisconsin law school Center for Patient Partnerships (<http://www.law.wisc.edu/patientadvocacy/>), and a related article including information about the Sarah Lawrence Health Advocacy Program. (August 14, 2005)

Also in "Being a Patient," Lin Osborn ('99), founder of Health Plan Navigator, an advocacy service specializing in managing health insurance issues and problems, is featured in an article on the "labyrinth" of medical bills patients face during and after illness. (October 13, 2005)

In October, the Health Advocacy and Theatre collaboration began a project on

caregiving with a seminar on intergenerational caregiving. Among our guest participants were Mary Ellen Geist, a former WCBS radio news anchor who left her job to care for her father who has Alzheimers, and Jane Gross, a *New York Times* reporter, who shared her experience as caregiver for her mother at the end of her life. Jane wrote about Mary Ellen's experience in "Forget the Career—My Parents Need Me at Home," a feature on women who leave professions to become family caregivers. (*New York Times*, November 24, 2005).

Business Week (October 24, 2005) cited the Health Advocacy Program in "Your Guide To The Medical Maze," about private companies that provide patient advocacy services; and the *Omaha World-Herald* (October 2, 2005) quoted Director Marsha Hurst in "Too Much of a Good Thing?", questioning whether disease specific advocacy had gone too far in commercializing fund raising.

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Health Advocacy Faculty News

Congratulations to Rachel Grob (HA '92), "Models of Advocacy" faculty and Associate Dean of Graduate Studies, for earning her doctorate in Sociology from the CUNY Graduate Center. Rachel and her dissertation advisor Barbara Katz Rothman were also awarded a Robert Wood Johnson Foundation Investigator Award in Health Policy. The study she will be working on as a RWJ Fellow, "Heel Sticks and Amnios: Disjunctures and Discrepancies in Prenatal and Newborn Genetic Screening," will build on her dissertation research, "Testing Baby: Parents' Perspectives on Genetic Diagnosis." This is the second Robert Wood Johnson fellow on our faculty: Peter Arno received a RWJ Foundation Investigator Award in Health Policy in 1998.

Patricia Banta (HA '00) has joined the "Models of Advocacy" faculty team this year to add her perspective as a policy and research advocate. Pat is Director of Government Grants Development at the Visiting Nurse Service of New York, and brings with her experience as a registered nurse and as a senior program analyst with the Office of Inspector General (DHHS).

Alice Herb, our attorney/bioethicist, was named October NYU Law School Alumna of the Month. Alice is leading the HAP & Theatre multimedia project on caregiving along with Marsha Hurst, Carol Levine, Director of the Families and Health Care Project at the United Hospital Fund and Shirley Kaplan of the SLC Theatre Department.

Terry Mizrahi ("Community Health") is off to Israel next semester where she will use her Fulbright Fellowship to do research on community development and citizen participation, and to teach at Hebrew University.

Sayantani DasGupta ("Illness Narratives") and Marsha Hurst are completing their anthology of women's illness narratives, *Stories of Illness and Healing: Women Writing Their Bodies*, to be published by Kent State University Press as part of their Literature and Medicine series. Sayantani has also co-authored "Teaching Cultural Competency through Narrative Medicine: Intersections of Classroom and Community" with colleagues at Columbia University and the Alianza Dominicana, Inc. (*Teaching and Learning in Medicine*, 18(1), 14-17). Alice and Marsha published their article, written with audiologist Abbey Berg (Pace University and Columbia University) on "Cochlear Implants in Young Children: Ethics, Audiology and Advocacy," in *Journal of Clinical Ethics*, fall 2005.

Many HAP faculty presented papers or workshops. Sayantani and Marsha presented papers at the Oral History Association in November on "Oral History and the Teaching of Health Care Professionals" and "Illness Narrative and Oral History: Keeping the Narrative Tools of Advocacy Accountable." Marsha's paper was delivered by HA graduate Pat Stanley ('05). Constance Peterson ("Models") presented a poster on "'Yellow Alert': A Systematic Plan for Avoiding Ambulance Diversion/Bypass" at the International Conference on Emergency Medicine in Montreal in June. Rachel Grob and Marsha Hurst led a workshop entitled "Bull's Eye—The Patient's Voice at Front and Center: Educating for Advocacy at Sarah Lawrence College" at the November Vancouver conference on "Where's The Patient's Voice in Health Professional Education?" Lois Steinberg and Marsha prepared a

paper, which Lois delivered at the Oxford Round Table on Aging, on "Retired Professionals as Peer Advocates: A Healthy Solution to a Sick Situation," based on their study of the volunteers in the SOS Medicare Program.

Marsha Hurst, Rachel Grob and Laura Weil collaborated with Meg Gaines from the Center for Patient Partnership on "Educating for Advocacy in Settings of Higher Education," for the Patient Advocacy Summit II in Chapel Hill, NC last March. This paper will be a chapter in a patient advocacy anthology edited by sociologist JoAnne Earp and colleagues at the Public Health School at UNC.

Check the Health Advocacy web site for additional and ongoing faculty news.

Read our new Health Advocacy Program blog and send us your comments.

The Health Advocacy at www.healthadvocacyslc.blogspot.com

HAP Grants for Curriculum Development and for Research

The Health Advocacy Program is thrilled to have received, in conjunction with the Human Genetics Program (HGP), two grants.

The first is an Implementation Grant from the Ford Foundation, through the Council of Graduate Schools, to help us develop and implement a certificate program in Applied Research Ethics to educate professionals for jobs in research-related work including the protection of human subjects, public participation in research design and review, and the development and operation of Institutional Review Boards. Watch for a more detailed format and curriculum description on our web site and in our next *Bulletin* issue!

The second grant, from the Jane Engelberg Memorial Fund, will support a two-year project entitled "Privileging Family Stories in Genetic Understanding: An Updated Paradigm for Genetic Counselors." The project team—Marsha Hurst, Rachel Grob, Caroline Lieber (Director of the HGP) and Linwood Lewis (SLC faculty member in psychology)—will conduct qualitative research to elicit the narrative voice of pregnant women as they discuss their knowledge and beliefs about heritability.

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, New York 10708.

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Recent Graduates and New Careers In Advocacy

Career choices of some recent graduates highlight new arenas of health advocacy.

Aging in Place. Deborah Guiffre (December '04) is working with Fredda Vladeck at the United Hospital Fund as senior program manager of the NORC Action Blueprint Project. NORCs are Naturally Occurring Retirement Communities and the Blueprint Project is aimed at pulling together what these communities have learned about supportive services for successful aging in place.

Research Advocacy. Marlene Krammer (December '04) is Assistant Director of Research Compliance at New York University School of Medicine. Marlene is one of a number of recent

HAP graduates who have turned to careers in research advocacy. (See Rachel's article about our new program in Applied Research Ethics to learn how HAP is involved in developing a new and much needed educational program in this area.) Marlene's classmate, Paula Rapp, has also moved into the research arena as Clinical Research Nurse Coordinator for the Department of Maternal Fetal Medicine, Yale University Medical Center. At the December PRIM&R/ARENA conference in Boston we had a mini-HAP reunion with Barbara Winrich ('01) and Christine Dyer ('02), who are also working in clinical research settings, and with Jan Loomis ('97) who is the IRB administrator at William W. Backus Hospital in Connecticut.

Private Sector Patient Advocacy. Naomi Cohen (September 2005) is at PinnacleCare where she is a patient advocate for families facing serious illness. Fortunately before Naomi graduated her last project was to get our blog up and running, for she is now too busy to contribute her own postings.

Geriatric Care Management. Also in private practice, but on her own steam, is Mary Tierney ('04), who is a geriatric care manager in New York, work that has been dear to her heart since she entered the Health Advocacy Program.

Disease-Specific Patient Advocacy. Mel Finklestein ('03) is carving out new terrain as the patient advocate in a hospital-based multidisciplinary Multiple Sclerosis practice.

Primary Care Capacity Building. Mel's classmate, Farrah Schwartz ('03) has just moved from cancer policy and research advocacy to Ontario's Ministry of Health and Long-Term Care as Project/Policy Analyst with the Health Results Primary Care Team.

Patient Representation. In a still much needed more traditional role, Ethlouse Banks ('02) has joined Janice Levy ('87) and other HAP graduates in the Patient Representation Department at Memorial Sloan Kettering Cancer Center. And Jane Cordova ('03) has moved to Long Island College Hospital as Manager of Patient Relations.

Please do tell us what you are doing. We need to hear from advocacy pioneers to keep abreast of new developments.

Three Health Advocacy Students Earn Awards

Health Advocacy students and graduates are being recognized. Two of our current students and one summer 2005 graduate were awarded scholarships or fellowships in recognition of their achievements as health advocacy students.

Nike Whittemore, a current Health Advocacy student who will graduate in May 2006 was named an AARP Scholar by the AARP Office of Academic Affairs. As an AARP Scholar, Nike received a \$5,000 scholarship and will participate in a leadership development program in Washington, D.C. in March 2006. Nike has been interested in advocacy for older adults since she entered the Program and has been working in particular on expanding her knowledge of long term care in anticipation of a career serving seniors.

Shawna Irish, a current second year (part-time) Health Advocacy graduate student at Sarah Lawrence College, is the new SOS Medicare Fellow at the Medicare Rights Center. She is the first MRC fellow specifically assigned to work on the Westchester County programs, and has been focusing on developing and implementing the new MRC counseling program on Medicare Part D—the Prescription Drug Benefit. Shawna has been extremely helpful educating her fellow students and the HAP faculty about this extremely complicated benefit, and will do a special workshop for SLC faculty and staff in the spring.

During the fall of 2005, **Lois McCourt**

was the post-graduate Health Advocacy Training Fellow in the Office of Liaison Activities at the National Cancer Institute (NIH, DHHS), working in the CARRA (Consumer Advocates in Research and Related Activities) program. Lois is the first to be awarded this fellowship. She graduated from the Health Advocacy Program in September 2005. Lois has been interested in both direct patient advocacy and program and policy advocacy. Her internship at Memorial Sloan Kettering Cancer Center followed by the NCI fellowship enabled her to immerse herself in both environments before making a career choice.

SAVE THE DATE!

Friday, March 31, 2006

The 2nd Annual Health Advocacy Program One-Day Conference

Genetics & Advocacy: Arenas of Engagement

Keynote by **Troy Duster**, Professor of Sociology, New York University; author of *Backdoor to Eugenics* and coauthor of *Whitewashing Race*
"Race and the New Genetics—Biotechnology, Biomarkers, and Biomarketing"

Other Arenas of Engagement include: politics and policy; identity; entrepreneurship; privacy; genetic discrimination; genetic testing and screening

Co-Sponsored by the Human Genetics Program and the Health, Science & Society faculty group at Sarah Lawrence College

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