

# HEALTH ADVOCACY BULLETIN

The Journal of the Health Advocacy Program at Sarah Lawrence College

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## Is There a Health Care Safety Net in Westchester County?

by *Desiree McDougall*

Over 3.2 million people in New York State live uncovered by health insurance. In Westchester County this translates to approximately 200,000 people, a group predominantly comprised of low income families, non-elderly adults, and Latino immigrants. At some point in time all will require health care services. Without these services this population, and in fact society as a whole, may suffer insurmountable morbidity.

Who does this group historically turn to for care? Can these sources of care remain viable in this era of health care finance restructuring? Is this population a prime focus of concern for county or state policymakers? How can health ad-

vocates best assist these individuals? These questions were the focus of a conference held March 15, 2001, sponsored by the Westchester Health Action Coalition and moderated by Lois Steinberg, HAP 2000. Bringing together county legislatures, administrators from community health centers and local hospitals, officials from the county Department of Health, and concerned community activists, the conference sought to define the un/underinsured population and examine the current status of their "safety net" providers.

One of the principal speakers, Lindsey Farrell, CEO of the Open Door Medical Centers (community health centers), examined the financing mechanisms that serve to shore up Westchester's safety net institutions, that is the network of

providers willing to provide care for minimal reimbursement. Traditional public insurance programs such as Medicaid and Medicare, in addition to other government vehicles (an increasing proportion of which are becoming privatized), such as CHIP (Child Health Plus), Health Source, Community Choice, Genesis, and the newly created program Family Health Plus\* (which has just been approved by HCFA), serve as one source of revenue for these institutions. Another source of funding comes from federal, state and county grants and contracts. A third source of support comes from "uncompensated care distributions," a pool of money derived from taxes paid on health insurance and health care services. This money is dispensed by Albany and redistributed to those institutions providing "charity care." While essential, this money is not always guaranteed to the institutions, making it difficult to insure the continued operation of their programs from one year to the next, or to plan for expansion.

Despite the best intentions of Open Door and other safety net institutions, there still remain gaps in services and resources needed by the un/underinsured. Two key areas yet to be addressed are the lack of insurance coverage for adult specialty care (children have access to specialized services through CHIP, however there is no similar broad based managed care resource for adults)\* and the absence of a cost-effective mechanism for supplying medication to these individuals. Immigrants face even more restrictions in access to services, as recent legislation has barred those immigrants who arrived in this country after 1996 from receiving any public health insurance for a period of five years following their arrival. Fortunately, children are excluded from this ruling since all children, documented or undocumented, are eligible for CHIP.

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# The Patient Eye

by Elizabeth Grant

Senator John McCain was recently quoted as saying that “the plight of the Irish is not alcohol but fair skin.” And this was certainly never more true than in my case.

Every summer of my young life was spent in the sun. My family had a summer house by the ocean and every year, as soon as school finished, my family (all nine of us) packed up our summer things and took off for the house on the New Jersey shore just across the street from the beach. And there we stayed until Labor Day.

Needless to say, in those days, the only protection we ever used was zinc oxide on our noses, which my dad had left over from his Navy days. It will come as no surprise to anyone today that in my mid-forties, skin problems started to appear which required attention – some serious, and others just a nuisance. I remember asking my dermatologist when we first met if she minded that I called her by her first name, because I had a feeling we were going to see a great deal of each another.

Seven years ago I had a basal cell carcinoma just millimeters from the corner of my eye. There was a possibility that it may have infiltrated the tear duct because of the proximity, but I was lucky and it had not. In the procedure to remove the tumor, the surgeon uses a surgical instrument called a Mohs that takes microscopic sections of tissue. The idea is to take as little tissue as possible and

still get clean margins around the growth, thus preventing a recurrence.

The procedure is performed under deep sedation. The surgeon removes a small section of tissue, and while I remain on the operating table, he looks microscopically to see if all the tumor cells have been removed. If there are still cells remaining, he returns to remove more tissue until the cells are normal. Because of the precarious location of the lesion, its close proximity to the eye, the repair had to be performed by an ophthalmic reconstructive surgeon who was located elsewhere.

The Mohs surgeon bandaged the lesion and sent me off to the ophthalmic surgeon in a cab. The area had been anesthetized, so there was no pain beyond a little discomfort. The repair was performed in the operating room in a hospital by grafting skin from behind my ear. When this occurred seven years ago I never dreamed that I would ever have to repeat the procedure, but I was wrong.

Several months ago I detected what looked suspiciously like another basal cell on the lower eyelid of the same eye. It was located directly on top of the tear duct opening, so there was little doubt that it had, this time, infiltrated the tear duct, which meant reconstruction of the duct would be required. It was a little less frightening this time because I was familiar with the procedure. I was, however, more concerned about the disfigurement because I knew that I would lose eyelashes, among other things, and no one would know how many, until the

Mohs surgeon could see how extensive the growth was.

I was to report to the Mohs surgeon’s office at 9 a.m. and expect to be there until noon, at least. And that’s pretty much the way it happened. I was ready to depart for the hospital at 12:30. I asked the surgeon if he would make sure that the area around my eye was sufficiently anesthetized so that it would stay numb until I went into the operating room at the hospital. There had been a significant piece of tissue removed, and all that remained was a hole. He assured me that I would be OK and that he didn’t want to inject any more anesthetic and cause swelling, thus making the repair more difficult.

So my husband and I were off to the hospital in a taxi and in a very short time we reached the area in the hospital where we were to wait for me to be taken to the operating room for the repair phase of this ordeal. When I arrived and checked in at the desk I informed the receptionist that the anesthetic was beginning to wear off and I was in considerable – and increasing – discomfort. She went into the operating suite and returned, informing me that

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## Thank you Karen Martinac

We in the health advocacy program wish to thank longtime HAP Bulletin co-editor Karen Martinac. Karen recently decided to step down as co-editor of the Bulletin, the better to attend to her own health and pursue other goals. (Karen detailed her journey as a patient in the Spring 2000 issue of the HAP Bulletin.)

Karen has been a tireless voice for patients and their advocates for many years. She truly understands the problems of the U.S. health care system from both sides of the bed. She worked hard to make the HAP Bulletin a quality publication of value to practicing health advocates. We look forward to her occasional contributions to the Bulletin, and thank her most sincerely for her years of dedicated service.

*Best wishes Karen!*

<http://slc.edu/~health>

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From The Editor:

# Let's Not Beat About the Bush: The New Administration Is Not On Our Side

By Deborah Hornstra

Health advocates must be both pessimists and optimists. After all, why become an advocate unless you think there are problems in the system and patients whose rights need protecting? But there's no point in doing the work unless you believe progress is possible and even inevitable. We know it will be slow and incremental. We realize we will continually have to make our case to people who are skeptical, or who have other priorities.

Even if we accept all this, however, it is difficult to come to terms with the meaning of the presidency of George W. Bush, and the current hold on all branches of power (save the Senate, thanks to Jim Jeffords of Vermont) by the right wing of the Republican party. Advocates need hope. They need to believe that those in high places will listen to them and support them as they advocate for patients, families, and health care workers. Unfortunately, all signs indicate that the new administration is not sympathetic to our arguments and is unlikely ever to champion our causes.

A quick scan of the headlines from the last few months is illustrative:

- Bush Opposes Bills for Patients' Rights
- White House Plans to Ease New Medical Privacy Rules
- EPA to Kill New Arsenic Standards
- Tobacco Interests Poised for Big Gains from Bush
- Bush AIDS Policy Remains Unclear

It seems that every day brings a fresh assault on self-determination, confidentiality, the environment, and common sense. There is more than we can keep up with, and none of it is good.

*Bush is no friend of patients' rights*

Sure, the new president says he supports patients' rights. He has to, because the idea has broad popular support even

within his own party. But the president refuses to sign any current version of the patients' bill of rights. Bush claims to favor most if not all provisions of the bill, and in fact almost all of its provisions, including access to specialists and emergency departments and allowing patients to select gynecologists and pediatricians as their primary care physicians, are already features of most health plans. So what's the sticking point? Bush doesn't want health plans to be punished financially if they deny care that was medically necessary.

tense industry lobbying against the act's crucial privacy provisions. But Bush and Secretary of Health and Human Services Tommy Thompson have expressed concerns with many of those provisions, and we can expect lax enforcement and an early call for Thompson to "review" HIPAA.

*Tossing Those Pesky Regulations*

Bush and his administration don't like regulations on business. Deregulation is a cornerstone of Bush's ideology. One of his first acts as president was to re-

peal the new ergonomics rules, carefully constructed after ten years of study by the Occupational Safety and Health Administration. Bush said the rules, which would have prevented 600,000 injuries a year, mostly to women in low-paying factory and office jobs, would cost businesses too much. He repealed them even in the face of evidence that treating the injured workers costs much more.

President Bush tried to halt the routine testing for salmonella of ground beef

used in the school lunch program, again using the excuse that the testing was too expensive (get used to it). He was forced to withdraw this proposal because the controversy it generated threatened to interfere with debate over his budget. He supports retaining the 1942 standard for allowable levels of arsenic in drinking water, despite recommendations by the World Health Organization and the National Academy of Sciences to reduce that level by 80 percent.

The flip side of all this deregulation is the clampdown on the public's right to information. As Bush loosens regulations on industry, he is simultaneously tightening access to information vital to the public health. The chemical industry has lobbied intensely for tighter restrictions on information about its methods, materials, and accident scenarios.

## EDITOR'S NOTE:

This issue of the HAP Bulletin is devoted to highlighting the work of some of our current students and recent graduates. In recent years, health advocacy has gone far beyond the patient's bedside. Advocates can now be found not only in patient representative departments but also on ethics committees and institutional review boards, in government, in non-profit advocacy organizations, as registered lobbyists, in academia, in media, and even in business. We hope you enjoy this special issue showcasing just a few of the diverse projects engaged in by Sarah Lawrence-educated health advocates.

The current bill allows patients whose claims have been wrongly denied to seek up to \$5 million in punitive damages from their insurers. Bush thinks noneconomic damages should be capped at \$500,000; he would disallow claims for punitive damages altogether. This he calls a "reasonable" way to discourage "frivolous" litigation and "excessive" awards. Bush says without the caps, the patients' bill of rights will cost insurance companies too much money, meaning it will decrease industry profit margins. So he won't sign a patients' bill of rights until it has been stripped of its muscle by the inclusion of an artificially low cap on damages.

To his credit, Bush did allow the Health Insurance Portability and Accountability Act of 1996 (HIPAA) to take effect as scheduled in April, despite in-

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Michael Brown, Director of Public Affairs at Sound Shore Medical Center in New Rochelle, summed up the important role of the safety net providers by stating "the buck stops with us." Noting that all of Westchester's safety net institutions, such as Sound Shore's emergency room, face precarious financing situations, Brown described how their financial dependency placed them squarely in the midst of what he called the "tense" relationship between state and federal funders, and that this dependency made them subject to increasingly complex regulations. In addition, changes in health care financing mechanisms such as those occurring under managed care have resulted in increased provider accountability for the safety net providers but have provided few additional dollars.

The Honorable Thomas Abinanti of the County Board of Legislatures, chairman of the County Health Committee, acknowledged the importance of safety net institutions as "front line fighters in the health care battle." He pointed out that the county legislature recognizes and supports the important work of these centers. This past year their recognition translated to allocation of \$2.6 million to four community health centers in Westchester, including Open Door.

However, as Abinanti indicated, county funding alone cannot insure the continuous operation of these institutions. State support and funding is also crucial to their viability, particularly since our system of government is one in which the bulk of the power (and decision making regarding allocation of money) lies with the states. He reminded the audience that Westchester County is

a valuable resource for New York State and in fact state government bodies will "occasionally" capitalize on successful models of health care delivery initiated by the county.

Naomi Matusow, State Assemblywoman from the 89th district, energized the conference by citing several examples of successful grass roots movements, which she said "can make a difference." She passionately urged everyone to write their legislative officials to inform them that, as registered voters, they care about crucial health care issues such as broadening insurance coverage and increasing the funding for safety net institutions, and also to remind them that their actions on these fronts would be "carefully monitored."

Dr. Jean Hudson, Deputy Commissioner for Community Health Services of the Westchester County Department of Health, concluded the first half of the program on a pragmatic yet optimistic note by sharing her guiding philosophy, "Build from where you are and capitalize on that." County Legislator Lois Bronz also attended the conference, and U.S. Member of Congress Nita Lowey and State Senators Nicholas Spano and Suzi Oppenheimer sent delegates to represent their offices.

Mark Hannay, director of Metro Health Care Campaign, a sister organization of the Westchester Health Action Coalition, directed the second half of the conference, focusing on consolidating support for safety net providers and increasing the momentum of the movement for universal health coverage. He asked those present to collect and share patient anecdotes that recounted difficulties with health insurance or health care providers. These types of stories serve as powerful motivating forces when garnering support for health care and insurance reforms.

Hannay also discussed two key measures awaiting discussion at the state legislative level. One involves possible reconfiguration of the bureaucratic state Medicaid application process. Hannay noted that the process as it exists today prevents many qualified applicants from applying for Medicaid and has hindered the approval and implementation of the Family Health Plus Program. Hannay also discussed a measure pertaining to the monitoring procedures of insurance companies. Until recently insurance

companies intending to raise their rates by more than 10% were required by state law to hold a public hearing. The recent expiration of this law has resulted in the absence of any prospective review mechanisms regarding insurance rate hikes. State legislatures are planning to review the need for the reimplementation of an oversight mechanism and need to be reminded how crucial this measure is to keeping insurance premiums affordable.

Overall the conference did an admirable job in acknowledging the increasing diversity of the un/underinsured population in Westchester County, in identifying gaps in the safety net (services that remain underfunded and inaccessible), and in presenting recent modifications in laws, government actions, and funding issues affecting health care delivery to this population. Anyone wishing to participate in further discussions regarding these or related issues is encouraged to call the Westchester Health Action Coalition at 914-693-9504 and is welcome to attend future meetings, held the second Thursday of each month at the American Red Cross in White Plains. ■

*Desiree McDougall will complete her master's in health advocacy in December 2001. She has worked as a pediatrician in community and public health clinics. As both a health care provider and a graduate student, Desiree's main focus has been on women's, children's and minority health issues. She is interested in pursuing work in the health policy arena.*

\*Family Health Plus is a comprehensive health insurance program that will service, at no cost, low income adults (up to 150% of the poverty level for parents living with a child, and up to 100% of the poverty level for those not living with a child) who do not have employer sponsored coverage, and are not eligible for Medicare and Medicaid. It would cover specialty services for qualified individuals.

\*\*The Westchester Health Action Coalition seeks to ensure that "everybody has access to health care that is affordable, comprehensive, and publicly accountable." Its membership includes official, voluntary and community organizations, as well as dedicated individuals in Westchester County, New York City as well as other state counties. WHAC holds public forums on health issues and legislation to "help citizens make informed decisions on health policy."

## Congratulations!

Congratulations to HA professor Terry Mizrahi, Ph.D., M.S.W., on her election to the presidency of the National Association of Social Workers (<http://www.naswdc.org>). More on Terry's dynamic new role in the national spotlight in the next HAP Bulletin.

# Lupus Advocacy Complicated, Challenging

by Jennifer K. Johnson

Lupus is an autoimmune disease in which the body actually attacks and destroys its own tissues and organs. Known as a “woman’s disease,” lupus is most commonly seen in women ages 20-40. Because little is known about the genetic and/or environmental causes of lupus, it is very difficult for physicians to treat patients with the disease, and there is no cure. Advocacy for this disease focuses on encouraging research that will help lead to a cure.

Lupus is one of several autoimmune disorders where the body’s immune system is not regulated properly and hence begins to have an immune response toward the body’s own organs and tissues. Organ specific autoimmune diseases affect only one organ or gland, whereas systemic autoimmune diseases involve a number of organs and tissues. Lupus is both an organ specific and a systemic disease. Discoid lupus is the organ specific form, and it is limited to the skin only. It is often diagnosed by taking a biopsy of an unexplained skin rash. The more common form is systemic lupus erythematosus, or SLE. SLE patients form antibodies to tissue antigens such as DNA, red blood cells, platelets, and leukocytes. Antibody/antigen complexes lead to hemolysis (bursting of the blood cells) and tissue damage as these complexes block blood vessels in tissues and damage blood vessel walls. In particular, the kidneys, lungs, and skin are damaged. Finally, lupus can be induced by drugs for hypertension and heart arrhythmia. Lupus is a chronic disease that cycles into periods of remission and flare-ups.

Lupus affects both men and women, but women have a disease incidence 10-15 times that of men. Women of African, Native American, and Asian descent seem to have an added incidence risk. For every one white woman diagnosed with lupus, four black women are diagnosed. In addition, the morbidity and mortality rates of blacks with lupus are higher than for whites. Approximately 16,000 Americans have lupus.

The largest lupus advocacy organization in the world is the Lupus Founda-

tion of America. LFA was established in 1977 as a grassroots volunteer organization. The group still has a large volunteer base, with 45,000 members in 93 chapters in the United States, and more chapters abroad. Advocacy on the community level is performed through chapter newsletters, community health fairs, support groups for patients, and referral services for physicians and medical centers. On a national level, the emphasis of the advocacy is on raising donations to fund research to learn more about the disease. An important part of this research lobbying force are the medical professionals who are involved because they are frustrated at their inability to treat lupus patients effectively due to the current lack of scientific knowledge.

There are a number of other advocacy organizations that work separately, but very few have the large-scale, national information base that LFA has. Virtually every state has its own lupus organization that works for patients on the state level. A number of chat rooms and online journal clubs have been established by nurses, most of whom have the disease (or another female-specific disease such as fibromyalgia) themselves. Given the nature of lupus, with its disproportionate impact on young women and women of color, there are also advocacy organizations aimed specifically at those groups of patients.

Lupus advocacy involves a number of issues that affect its efficacy. These issues include a lack of medical knowledge of the disease, the disparities in disease progression in people of color, and

the unstable nature of the disease. These issues have made it more difficult for lupus advocates (as opposed to say, breast cancer advocates) to effectively push for legislation and policy changes that benefit lupus patients.

The lack of medical knowledge is a serious impediment to developing an effective approach to lupus advocacy. Should lupus advocacy be framed as a women’s health issue, such as breast cancer has been, even though there is no certain medical reason why women are more frequently affected than men? Should the disease be approached from the stance of a disease of people of color, even though there is no certain medical reason why the disease particularly affects women of color? Most importantly to the advocacy fight, the lack of medical knowledge means that the disease is not very visible to the community at large, which means there is no real community backing for lupus advocacy.

Disparities in disease progression in people of color has led advocacy for lupus to be grouped with advocacy for other race-specific conditions such as diabetes, hypertension and obesity. The website “What Every Black Woman Should Know About Lupus” (WEBWSKAL) emphasizes that lupus is just one of many diseases where morbidity and mortality are higher for blacks than for whites, and describes this as just another example of the poor state of health care for people of color. This movement could serve as an effective means of advocacy for lupus, if former

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## END-OF-LIFE SEMINAR SERIES

In conjunction with the Jansen Memorial Hospice in Bronxville, the Health Advocacy Program will offer a series of lectures and seminars as a non-credit course entitled “Understanding the End of Life.” The course, to run from October 2001 to May 2002, will cost just \$10 per session (\$50 for the set of six sessions). Sessions will run in the late afternoon and early evening.

Series topics will include death in literature, pain management, advance directives, and hospice care. Each seminar will feature guest speakers from the healthcare community. Sessions will be interactive and participants will be invited to share their own experiences and ask questions of the guests.

For more information, visit the HAP website at <http://slc.edu/~health>.

# Let's Not Beat About the Bush: The New Administration Is Not On Our Side

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They want a world in which Erin Brockovich could not have found out what PG&E was doing in the California desert, and under Bush, they may get it.

We can also expect to see less vigorous enforcement of the Americans with Disabilities Act, signed into law with much fanfare by Bush's own father. Since its passage a decade ago, the ADA has been viewed with increasing hostility by business leaders, who resent the cost of compliance. Already the Supreme Court has declared that people with disabilities who are state employees cannot sue their employers for violations of the ADA. Surely this is a first step in the deliberate erosion and eventual elimination of the ADA's hard-fought protections.

## *Moralistic, Not Compassionate, Conservatism*

The Bush administration views public health problems such as AIDS, drug abuse and teen pregnancy as moral issues. Attorney General John Ashcroft is opposed to treating drug abusers as addicts instead of criminals. He has expressed his opposition to diverting resources from law enforcement into drug treatment and prevention and has even suggested that the meager funds now allocated for drug treatment should be earmarked for more law enforcement instead.

Bush is also opposed even to studying needle exchange programs, saying conducting such research itself sends the "wrong" message. When it comes to cigarettes, though, the message is apparently "just say yes." Bush's budget offers less than \$2 million to fund the Justice Department's lawsuit against the tobacco industry; the lawyers working on it say they need about thirty times that to prevail. The states were winning these suits and using the damages recovered from the tobacco companies to fund essential health programs. That's all over now.

Bush seems to have no AIDS policy whatever, except to favor his supporters in the pharmaceutical industry, the ones who peddle the expensive cocktails that keep people with HIV alive and reasonably well, and who want their patents and profits protected, even in impoverished countries ravaged by disease. Bush has eliminated the AIDS

adviser's position on the National Security Council and has let other AIDS-related offices languish.

The new president's first official act was to reimpose the Reagan-era gag rule known as the Mexico City Policy, which forbids U.S. funding of any overseas group that even counsels its patients about abortion. It was an audacious act that will greatly impact women seeking family planning services worldwide. Since in many countries the same organizations that provide family planning services also provide HIV/AIDS counseling and treatment, Bush's withdrawal of this funding will also cause grave harm to people with HIV and AIDS who have nowhere else to turn.

Bush has eliminated insurance coverage of contraceptives for federal employees. He would like to see *Roe v. Wade* overturned and the abortion question returned to the states, many of which would no doubt outlaw it. He is against expanding access to RU-486 and the morning-after pill, and Attorney General Ashcroft is personally opposed to certain forms of contraception. The Bush team's opposition to abortion extends to research on embryonic stem cells, which are thought promising sources of treatment for many serious disorders. The administration is also opposed to comprehensive sex education and promotes exclusive use of an abstinence-only curriculum that does not teach sexually active teenagers how to protect themselves from pregnancy and disease.

Right-to-die advocates will not find support from a government that considers euthanasia part of the so-called culture of death that also includes abortion. Bush's adamant opposition to doctor-assisted suicide is on record and, based as it is on religious belief, unlikely to change.

## *Forget about universal health care*

Bush has said he is "absolutely opposed" to a national health care plan. Indeed, the new administration is not overly concerned about the uninsured. When Bush spoke before the American College of Cardiology in March, he mentioned only one idea for making health insurance affordable. Can you guess what it was? Capping those punitive damages again! According to Bush, the only reason health insurance is

unaffordable is because of all the frivolous lawsuits against insurers (including employers who self-insure), which his low-cap version of the Patients' Bill of Rights would greatly remedy.

The Bush budget does next to nothing to extend health insurance to the 42 million Americans who now lack it. The president offers mostly tax relief, in amounts insufficient to cover the cost of purchasing private health insurance. The new party in power likes to downplay the significance of the high number of uninsured, suggesting that many of them lack health insurance by choice, because they are young and healthy and do not feel they need it. Republicans also claim that many are uninsured only for brief periods of time, for example in between jobs, and that therefore the problem is not as serious as the raw numbers might indicate.

As Governor of Texas, Bush actually fought hard NOT to provide health insurance to poor children. He made sure the state took its time enrolling Texas's one and a half million uninsured children in the Children's Health Insurance Program (CHIP). CHIP was enacted in 1997 but Bush aggressively delayed implementation until 1999, and then fought to limit participation to children with family incomes at 150% of the poverty line, though the federal law allowed covering kids up to 200% of poverty.\* He did this because he didn't want the "spillover" that would occur when the kids turned out to be eligible for Medicaid (with its threshold of 100% of poverty). He also did it to please his fundamentalist Christian backers, who didn't like the idea of federal health care funds being used for, among other things, abortions for teenagers.

President Bush's budget proposes a whopping 86 percent cut in the category of programs for people without health insurance, including the well regarded community access program, which linked providers of last resort into a coordinated safety net to serve the uninsured. His budget also cuts federal spending for the training of doctors, nurses, and other health professionals by an incredible 60 percent, at a time when the entire nation is facing a severe shortage of nurses, and many areas are still underserved by doctors. And the Bush budget includes cuts in programs that

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address child abuse.

## Show Us the Money

Reimbursements to hospitals will continue to decline under the Bush administration, and hospitals will have to make do with less. The aforementioned nursing shortage, already acute, is likely to worsen in the face of further budget cutbacks. More nurses cannot be recruited at the current level of pay, which averages between \$40,000 and \$45,000.

In both parties, there is widespread support for making prescription drugs more affordable to people on Medicare. At issue is whether such benefits should be added to Medicare or whether, as Bush believes, affordable prescription drug coverage can be provided by private insurance companies. To add a prescription drug benefit to Medicare would of course cost money, and most observers think adding the benefit will require the government to control the price of drugs, a prospect that strikes fear into the pharmaceutical companies. We can get an idea where Bush stands here by looking at who he appointed to decide whether we can afford the benefit and whether it will require price controls on drugs—a former executive of Eli Lilly.

Many think Bush will eventually have to raid the current Medicare surplus to pay for his missile defense plan and to fund his massive tax cut. Efforts to wall that surplus off and prevent its use for other purposes have so far faltered. In the face of an attempted raid on Medicare funds, advocates must be vocal about the need to protect the integrity of the program for future generations.

## The Company He Keeps

Let's wonder where Bush gets his ideas on health care policy, the president's major health care adviser is Deborah Steelman, a lobbyist for the industry who has represented Aetna, Cigna, Pfizer, United Health Care, and Prudential, among others. His other senior advisers all have industry connections or are pro-market academics or researchers. Not a single one is a practicing health care provider or health ad-

vocate. Not a single one represents a patient-oriented perspective. There is simply no one at Bush's table who speaks for patients, families, or health care providers.

Running throughout Bush's philosophy is the idea that health care is just a business like any other, without any moral component. And so, what is the appropriate response to this new state of affairs? We will all have to answer that for ourselves over the coming months. Certainly surrender is not an option. Aggressive outreach is more important now than ever, when there is a dire need for advocates to help people understand the system, the issues, and the ways in which change is possible.

I suggest we regroup, develop new "strategies" and work harder than ever to communicate the importance of the patient's perspective. We needn't all engage on the national level. This is an excellent time to make progress in our states, counties, and communities, to rediscover the power of grassroots organizing.

We must not be silenced. We must dis-

cuss the issues of the day with our friends and colleagues, write letters to the editor and op/eds for publication in our local newspapers, and support advocacy efforts with our money and our labor, as we support sympathetic political candidates with our money and our votes.

There are already signs that President Bush is serving as a provocateur, motivating previously complacent folks into protecting their interests. When Jim Jeffords left the Republican party in May, he put the Senate Democrats in a position to curtail at least some of Bush's excesses. If a new wave of social activism is indeed inspired by this administration's extremism, then at least one good thing will emerge from the Bush II era. And I shall end on that optimistic note, since we can't be pessimistic all the time, and we must have hope. ■

*\*Did you ever wonder why the poverty level is set so ridiculously low? It's because it's based almost entirely on the price of food, which is relatively stable, not on the price of housing, which has inflated wildly and which is where most poor families get hit hardest.*



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# The Patient Eye

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someone would be right with me.

We sat and ten minutes went by. Then fifteen, twenty minutes, and the pain was getting more and more intense. I stood and walked to the desk again. I asked the receptionist to go back into the operating suite and send someone out to speak to me, reminding her that my anesthetic was wearing off and I needed to be tended to as soon as possible. She started to tell me that she had already gone in before and I told her that I was aware of that and I wanted her to go in there again. She reluctantly got up, walked in and in a matter of seconds a nurse came out and informed me that my surgeon was ready for me and whisked me off to prepare for the last lap in a long and grueling day. I lay in a room with other patients who were also being prepped for surgery.

My surgeon came in briefly and before long someone was beginning to start an IV in my hand. She was involved in a conversation with someone else in the room and stuck my hand several times before she was able to start the IV, all the while having a completely unrelated conversation with her coworker. Each time she stuck the back of my hand it felt like burning hot coals. After a two-and-a-half hour repair procedure I was in the recovery room eager to go home and put an end to an excruciatingly long and tedious process. The doctor gave my husband a prescription for pain for me and at 5:30 p.m. we were on our way home.

I was surprised at how foggy I was as compared to my previous experience in 1993. My throat was very sore and only then did I realize that I had been given general anesthesia. My understanding had been that I would have deep sedation for the repair just as I had for the Mohs surgery. I was wrong. At home I settled down to try to sleep but found that I was in too much discomfort. I took the pain medicine the surgeon had prescribed and found no relief. At 4:30 in the morning I finally read the label on the prescription to find that it was little more than Tylenol. Fortunately I had pain medication left over from a prior procedure that allowed me to go to sleep in some comfort.

The following morning when I woke I was puzzled by intense tenderness on one side of my nose. Neither the sutures behind my ear nor ones around my eye caused me any significant discomfort. I could not figure why my nose was too sore to touch, let alone blow or even wear my glasses. The plastic surgeon had casually mentioned that they would "go through the nose" at some point, but he never elaborated. There was one long bruise that ran from just below my eye to my chin. Apparently there was a small tube inserted from my lower eye lid into my nose in order for a new tear duct to form. The tube is to stay in place for about a year and then be removed, leaving a newly formed tear duct.

When I went for my first postoperative visit a week later the surgeon en-

tered the room and in a jocular fashion asked me, "So, which hurt more, your ear or your eye?" I answered him that neither hurt but my nose was extremely tender. He answered by saying "Gee, we barely worked on the nose." Period. No further discussion.

The point of describing this whole experience is to illustrate how a patient's pain seems, at least in my experience, to have been given a very low priority. Although precision is crucial, health care providers need to remember that what they are working with is a whole being, not just a vein on a hand or a rebuilt tear duct. When a patient is in pain all their energy goes toward dealing with the pain, not healing.

Last year I did field work in a shelter for battered women and the staff attended a meeting with a Family Court judge to discuss how domestic violence is handled in the court system. The judge said that she had attended a conference of judges recently and was floored by what she described as "gross indifference" on the part of the judges when it came to really understanding what being beaten by someone twice your size actually feels like. She asked the group of judges to stop for one minute and try to imagine what it feels like to actually be dragged by your hair. They all agreed that they had never thought about it in those terms before. The message is the same for health care providers, who should all be required, at some time in their training, to put on a hospital gown, with the back open, and actually experience some of the procedures that they perform. Perhaps next time they won't be so casual about starting an IV. Perhaps, when a patient says that she is in pain they will respond a little more promptly. Maybe they will think twice about sending someone home with little more than Tylenol for pain after a complicated surgical procedure. ■

*Elizabeth Grant will graduate from Sarah Lawrence in May 2001 with a B.A. in Liberal Arts and a solid foundation in psychology. She will enter the SLC master's program in Health Advocacy in Fall 2002. Elizabeth, a New Yorker who formerly volunteered in the Child Life Program at New York Hospital, is especially interested in bioethics and the teaching of humanizing medicine to medical students.*

## Professional Development Series Debuts

Spring 2001 saw the inauguration of a series of free professional development workshops with guest faculty, jointly sponsored by the Health Advocacy Program and the Human Genetics Program. The workshops were kept small to take advantage of Sarah Lawrence's trademark seminar format.

In February, the series featured SLC psychology professor Linwood Lewis, Ph.D., on the challenges facing researchers who work with vulnerable populations, as well as what IRBs look for in assessing ethical research with vulnerable populations.

The March program brought Gabor

Keitner, M.D., of Brown University Medical School and the Rhode Island Hospital, to speak on the ethical complexities of running clinical trials.

In April, Arthur Frank, Ph.D., professor of sociology at the University of Calgary and author of *The Wounded Storyteller: Body, Illness and Ethics* (University of Chicago Press 1995), returned to his native northeast to lead program participants in a discussion of illness narratives. Dr. Frank's current work involves learning how and why people who have been seriously ill turn this experience into advocacy, art or other public expression.



# Correspondence: Impressions of a Bankrupt Hospital

by Judy Roothaan

I spent a couple of days last week roaming around a bankrupt hospital in Chicago. I was there to buy filing cabinets at a liquidation sale, but I got added value: an experiential, impressionistic education in some of today's issues in medical care.

The hospital was built in the 1920's by a railroad company to provide medical care to its employees. The company name is still incised in stone over the handsome marquee that extends for 30 feet over the curved drive that leads to the hospital entrance. About 20 years ago, the old hospital closed down. It was taken over by a consortium of doctors who proclaimed its new identity with billboard-sized placards, and aggressively marketed it as a facility to serve the residents of the low/moderate income community nearby.

At first, things seemed to go well. But after a while troubling rumors began to circulate. There was talk of mismanagement, even of fraud. One director became the subject of a major TV exposé. There were hints that he lured elderly patients into unneeded cataract surgery, to be performed at outpatient clinics that he owned. There were allegations that the hospital filled empty beds with healthy people and then billed Medicare for services that were never performed. Finally the Feds stepped in. One doctor avoided indictment by reimbursing the government for \$12 million in unfounded Medicare claims. But others were indicted; I believe their cases are still pending. A few staff doctors made a last ditch effort to rescue the operation. But it was too late. Years of bilking the government and milking the hospital had taken its toll. Toward the end, there was no money to pay the staff. Finally bankruptcy proceedings were initiated, and the hospital closed its doors.

The hospital building is elegant and its location is gorgeous, right across the street from one of our most beautiful lakefront parks. It will soon be turned into condominiums.

I learned from the liquidators that their major business comes from hospital closings; they claim to average one a

week. They just liquidated Mount Sinai in Cleveland. I knew about hospital closings, but I had no idea they were so frequent. Do you happen to know what the numbers are? The liquidators' website is <http://generalassetrecovery.com>. It's interesting.

The luxury in this hospital, and the evident waste, were obscene. In the board room: a stunning 30-foot conference table, now priced by General Asset Recovery at \$1500, surrounded by mahogany swivel chairs, on wheels, with brocade upholstery tacked with closely spaced brass-headed nails, now going for \$25 each. A mahogany console was topped by a 15-foot slab of green marble. I saw top quality file cabinets, mahogany desks, state-of-the-art workstations, expensively framed pictures. Only the beds looked cheesy.

Apparently, the staff just cut and ran—everything was left behind, even the snacks in people's desk drawers. The files were filled to the brim with personnel records, nursing and medication

schedules, quality assurance forms, and on and on. I saw no patient records, but I wasn't really looking; I just glanced at the stuff while I was emptying out the file cabinets I bought.

I saw drawers full of cancelled checks, none under \$50,000, most for more. Reams of accounting data were piled all over the place, in drawers and out. Those must have had patient names. I couldn't begin to count the procedural notebooks; there were shelves full of 2-inch thick ones that contained accounting guidelines. Could these have been multiple copies of the same regs, or were they all different? I didn't check.

The most fascinating items pertained to Medicare rules and regs. Did you know that the Commerce Clearing House (CCH) publishes 2-inch thick, hard-cover volumes of Medicare regs? I think there's a 4-volume set published each year. A friend of mine, who does graphic design for the CCH, told me that

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## *What is up with online polls?*

**H**ave you encountered poll results on the Internet that were hard to believe and wondered, what's up with that? There's a good reason why online polls look funny—they're completely unreliable. Let's look at why.

- Internet users do not accurately reflect all Americans. Though the digital divide is narrowing, Internet users are still disproportionately wealthy, educated, white, urban and male. Internet penetration is nowhere near the level of telephone penetration.

- Email addresses cannot be generated randomly as can telephone numbers. So online polling organizations cannot contact people to ask them questions. Instead they must wait to be contacted by people who self-select, meaning the sample is not even a random representation of Internet users. This alone has caused the chief methodologist for Gallup, which does not conduct online polls, to call them "fatally flawed, all junk."

- Special interest groups employ vol-

unteers to monitor the large media websites and alert their members by email when there is a poll in progress. Since respondents self-select poll participation, it is incredibly easy for even a loosely organized group to summon hundreds or thousands of eager poll respondents in a matter of minutes.

- Scientifically conducted polls take into consideration the fact that the order of the questions and the multiple-choice answers given has an effect on people's responses. They routinely mix these up to control for that effect. But online polls always present the same questions (and possible answers to those questions) in the same order. This exacerbates the natural tendency (displayed humorously by Kevin Kline's character in "A Fish Called Wanda") to forget the middle choices and remember only the first and last.

So next time you see an interesting-looking online poll, go ahead and click "View results." Just don't take them too seriously.

# Correspondence: Impressions of a Bankrupt Hospital

*Continued from page 9*

they are mandated by law so that the public can have access to the Medicare regs. Have you ever heard of a patient who purchased them? Did you ever see any of these during your studies?

I scanned a loose-leaf notebook with weekly news bulletins on proposed and actual changes in Medicare regs. One thing became plain to me: you and I could email each other about Medicare regs every day for the rest of our lives, and we'd never get even remotely close to covering all of them.

I brought home a copy of *St. Anthony's DRG Guidebook* (ISBN 1-56329-470-2 DRG-98). One-inch thick, spiral-bound. Its back cover says that it is "a comprehensive reference to the DRG classification system. Grouped by major diagnostic category, this resource provides detailed information on the diagnosis and/or procedure codes that identify a specific DRG...All the facts of the DRG system are provided, including the relative weight and geometric and arithmetic mean lengths of stay..."

I thought *St. Anthony's* referred to a hospital. But it doesn't. It's a publishing house, and it claims to be "widely regarded as the leading expert in coding and reimbursement resources." The information in the book "is taken from the official data published by the Health Care Financing Administration (HCFA) in 'Medicare Program: Changes in the Inpatient Hospital Prospective Payment System and Fiscal Year 1998 Rates, Final Rule' (*Federal Register* 62, no. 168, Aug. 29, 1997, pages 45970 through 46091)."

You probably know something about DRG's, but let me share my experience with them, and what I learned from *St. Anthony's* book. I first heard about them when my mother was hospitalized with a stroke that left her paralyzed, unable to speak or even swallow. After five days, I was told she had to move to a nursing home. I was stunned, and I expected her doctor to share my concern. I thought that, as a champion of patient rights, he'd surely be opposed to the DRG's.

But he wasn't and, as he talked, I found out why. He told me that strict treatment limits were necessary if we were to have a system that provided equal care for everyone. He added that there were scam-artist doctors who defeated

the system by fraudulently prescribing additional procedures, thereby producing new DRG's and longer hospital stays. He would never do such a thing.

But he did, not out of fraud, but because the nursing home refused to take my mother unless an additional procedure was performed. A bit later on, I got her into a facility that restored her swallowing, and might have restored her speech if we'd intervened earlier. So much for "unnecessary procedures."

I got a further insight into DRG's a few years later from a good friend of mine (someone I met at the Forum) who had worked for the AMA around the time HCFA established the DRG's. She told me that although the medical data were provided by doctors, the coding and weighting of procedures were done by industrial engineers. The goal was quality control, but soon it became cost control too.

Which brings me to my latest discovery. I'd always wondered if the DRG's were adjusted for age. Thanks to *St. Anthony's Guidebook*, I finally got the answer. There are two brackets: under 17

and over 17. Can you believe it? This looks like an area for elder advocacy.

That's the end of my value-added experience at the hospital liquidation sale. But I hope it's not going to be the end of my adding value to what we know about medical care, costs, rules and regs. Remember that meeting on health care services that you and I attended last month? After I heard the politicians, pollsters and pundits speak, a phrase kept going through my mind. It's from a TV ad by a discount clothing store in Chicago. It says: "An educated consumer is our best friend." Well, an educated medical consumer is medical care's best friend and every patient and every doctor's best friend. If we don't know what's going on, our politicians will never ever give us what we really need and really want. ■

*Judy Roothaan is a Chicago-based sociologist and community activist. She is on the board of the Older Women's League of Illinois. This was adapted from a letter she wrote to a friend who is a health advocate.*

## Lupus Advocacy Complicated, Challenging

*Continued from page 5*

President Clinton's Initiative to Eliminate Racial and Ethnic Disparities in Health is continued by the new administration.

The unstable nature of lupus poses an additional challenge to advocates. The disease manifests almost completely differently in every person; periods of remission differ, as do symptoms. Symptoms of lupus, which include pain inflammation and tissue injury, are not particular to the disease, making it more difficult to diagnose. Advocates can encounter difficulty fighting for patients' needs because it is not really clear what those needs are.

Lupus advocacy is very well organized, but not enough is known about the disease to turn it into a "cause" that will garner legislators' attention. The fact that the disease disproportionately affects women and people of color does not enhance its importance to legislators. Perhaps a more effective way to advocate would be for the LFA and other organizations to appeal directly to medical institutions for research—in a sense,

taking the research into their own hands. This is a technique being used by the WEBWSKAL website. These advocates are establishing their own connections with the Morehouse School of Medicine in Atlanta and Meharry Medical College in Nashville in an attempt to learn more about lupus. ■

*Further Reading:*

Kuby, Janis. *Immunology*. W. H. Freeman and Company, United States, 1994.

Lupus Foundation of America: [www.lupus.org](http://www.lupus.org)

WEBWSKAL "What Every Black Woman Should Know about Lupus": [www.lupusminorities.org](http://www.lupusminorities.org)

*Jennifer Johnson will receive her M.A. in Health Advocacy in May 2001. This summer she will do a genetic counseling placement at the University of Medicine and Dentistry of New Jersey in Newark, and in May 2002 she will receive her M.S. in Human Genetics. She intends to work as a genetic counselor or as an advocate on the policy level, focusing on minority and women's health.*

# An Unusual Placement Experience: The Center for Multicultural and Minority Health

by Jody Harris

Last year I had the opportunity to intern at New York Presbyterian Hospital/Cornell Medical College, in the Center for Multicultural and Minority Health. I had an interest in cross-cultural issues in the doctor-patient encounter, so the placement seemed like it could be interesting. I worked with an attending who developed and taught a cross-cultural curriculum to interns—a patient-based approach to treating a culturally diverse patient population in the primary care setting. My site supervisor was very enthusiastic about me joining the work and we tentatively agreed that I would do some type of evaluation of their curriculum.

I began my internship as an observer of the teaching sessions. I found it very interesting and was impressed that some of the interns came into the class with a prior appreciation of the importance of cultural competence. Key aspects of the four two-hour sessions were: 1) the use of case-based learning exercises with “paper cases,” observing a video-taped encounter with an actor-patient, and a practice session with an actor-patient; 2) discussion of the importance of eliciting the patient’s “explanatory model,” or the meaning of the illness for the patient by asking the right questions, listening to the patient and being respectful of the patient’s beliefs; 3) exploration of the social and cultural factors that may impact on the individual; and 4) information on how to negotiate a mutually acceptable plan of care. I sat in on three sessions. Following each class, we returned to the office to discuss how it went.

To augment my understanding of the issues, my site supervisor suggested I do a literature search on the subject of evaluation of the doctor-patient encounter. I was given the names of several researchers with expertise in this area. Most of the articles I found, however, were descriptions of evaluation studies analyzed quantitatively, and I did not get much out of them. I was also given a copy of “Culture, Illness and Care: Clinical Lessons from Anthropologic and Cross-

Cultural Research,” by Arthur Kleinman and Leon Eisenberg, from *Annals of Internal Medicine*, 2/87, Vol. 88, No.2. This article illuminated the concept that illness is culturally constructed, that there is a difference between the illness experience and the disease, and that for each person the illness has a certain meaning. Kleinman refers to that meaning as the

explanatory model of the illness and proposes a line of questioning to get at the patient’s explanation. These questions are basically the same ones taught in the cross-cultural curriculum.

After the course ended, it was a little unclear what I was doing there and they

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## Sociocultural and Linguistic Barriers in an Urban Academic Outpatient Practice: Observations from Doctors in Training

*Presented at the conference of the Society of General Internal Medicine, San Diego, May 2001.*

### *Abstract*

The purpose of this study was to identify residents’ perceptions of the socioculturally and linguistically based barriers they face in caring for a diverse patient population. We also attempted to determine whether, and in what ways, a required cross-cultural curriculum helped them deal with these barriers.

### *Methods*

We conducted structured interviews with the entire intern class of an urban academic internal medicine residency program (n=40). These were carried out with the stated goal of identifying general barriers to quality care for their patient population. Interviews were performed within six months of the completion of an eight-hour, case-based, cross-cultural curriculum. Residents were not aware of any connection between the research assistant who conducted the interview and the primary researchers who taught the curriculum. Probes for the interview focused on: general barriers to care, sociocultural and linguistic barriers to care, if and how they had been prepared to deal with these barriers and the type of training they had received, and whether the cross-cultural curriculum had helped them and affected their attitude towards these issues. Interviews were recorded, transcribed, and coded by two independent outside researchers experienced in qualitative analysis.

### *Results*

Several barriers to delivering care were identified:

1. Language differences between patient and resident
2. Limited time to address important cross-cultural issues in medical encounter
3. Understanding socioculturally-based patient expectations and perceptions of medical care (including mistrust)
4. Differences between patient beliefs and physician beliefs regarding disease and illness

Effect of cross-cultural curriculum on attitudes and practice:

1. Greater acknowledgment of the role of sociocultural issues
2. More probing into patients’ beliefs and practices
3. Overall very helpful in addressing barriers

### *Conclusion*

Residents cite several barriers to caring for their socioculturally and linguistically diverse patient populations. While they identified several benefits of a cross-cultural curriculum, they also highlighted the need for effective interpreter services and increased time to care for these patients.

*Authors: Joseph Betancourt, Weill Medical College of Cornell; Alexander Green, Weill Medical College of Cornell; Jody Harris, Sarah Lawrence College; Cassia Charles, Weill Medical College of Cornell; Bob Meyer, Weill Medical College of Cornell; J. Emilio Carrillo, Weill Medical College of Cornell*

# Results of HAP Literacy Study Reinforce Need for Family Health Care Decision Act

by Lois Steinberg, Pat Banta, and Marsha Hurst

The vast majority of American adults believe it is important to make their own decisions about health care, and wish to control those decisions even if they lose mental capacity at the end of life. Nevertheless, the percent of those having a health care proxy, living will or other legal document that indicates their wishes in case of such incapacity is estimated at between two and 30 percent. Many people believe they do not need such a document, assuming that their family or other loved ones will know their wishes and be able to make these decisions for them. Others may put off completing the form because they don't want to think about their own death.

These ideas about health care proxies may have serious and unforeseen

consequences for New York residents who are unaware that New York is one of only two states that do not allow family members who have not been named as agents in a health care proxy to make health care decisions for an incapacitated relative. In New York State, physicians are legally authorized to make recommendations about providing or withholding care which may or may not be consistent with what the patient would want. Some incapacitated patients are denied appropriate treatment, while others are subjected to burdensome treatments that violate their wishes and values.

The Health Advocacy Program recently conducted a study to determine whether advance directive literacy—the ability to read and understand patients' rights about medical decisions—has an impact on completing a health care proxy. The study was conducted among

210 elderly adults living independently in urban, suburban and rural counties in New York State. In addition to participating in a 25-minute interview about advance directives and end-of-life treatment decisions, respondents completed three types of tests to measure their own health literacy: basic health literacy, document literacy and advance directive literacy. Almost all respondents (87%) scored at the 9th grade level on basic health literacy, indicating they are capable of reading health care material.

The study's findings suggest that New York's law regarding end-of-life treatment decisions is inconsistent with the beliefs and preferences of many older residents. People who think their family will have the right to make treatment decisions for them see no need to sign a health care proxy or other legal document for this purpose. Furthermore, even educated residents with high scores

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## An Unusual Placement Experience

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didn't know quite what to do with me. With Marsha Hurst's encouragement, I proposed the idea of creating a project of my own. The initial idea was for me to interview the first-year interns to find out if they were learning and using the skills taught in the cross-cultural curriculum. After some back and forth, we decided that it would be better to find out directly from the interns what problems they faced in the doctor-patient encounter. The open-ended questions we asked were what general issues make the patient-doctor encounter difficult?; what specific social and cultural issues are difficult?; and is there any training they think would help them deal with these problems?

Armed with a tape recorder and the beeper numbers of all the interns, provided with a desk and phone several days per week, I was pretty much on my own. The participants were given a confidentiality statement to read. They were assured that their names would not be connected to their comments and that I would be the only one transcribing the tapes. I was a little nervous to start, but

soon realized that the interns had plenty to say. The challenge was probing for specific examples when general statements were made. It was slow going because I had to grab them in between patient visits in the clinic, before or after clinic, or up on the floors. After a couple of weeks, they brought in a research assistant to do some of the interviews and that was a big help.

While transcribing the interviews, I realized where I had missed opportunities to probe for more details. But we gathered a lot of good information and my supervisor and his colleagues were very excited about what these interviews revealed. An abstract based upon the material was presented last spring at a meeting of the Society of General Internal Medicine, entitled: "Sociocultural and linguistic barriers in an urban academic outpatient practice: Observations from doctors in training." (Sidebar, page 10.)

My site supervisor and others at the Center for Multicultural and Minority Health were great to work with. They were enthusiastic about their mission and treated me like a colleague. Unfor-

tunately, the supervisor, who was the driving force there, recently left the institution for another position out of town so it is unclear whether this will continue to be a placement site for HAP students.

I went into this internship already interested in cross-cultural issues. The philosophy of the HAP curriculum has influenced how I view cross-cultural problems in the medical encounter. The curriculum teaches us to reject cultural generalizations, and encourages doctors and other medical professionals to consider the social and cultural context of each individual. I have come to realize there is a role for advocates in medical education and the training of more humane doctors, and I hope to make a contribution to that training. ■

*Jody Harris is a Los Angeles native who holds a B.A. in English Literature from Brooklyn College. She is a part-time student in the health advocacy program and a volunteer at the Brooklyn Children's Museum and the New York Public Library. At the library, she is a facilitator of discussion groups for students of English as a second language.*

# Results of HAP Literacy Study

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on a basic health literacy test have difficulty understanding the complexity of the New York law.

*Among the study's findings:*

- Most respondents did not have a health care proxy or other advance directive.
- Only one-third of respondents have a health care proxy designating an agent to make health care decisions for them. Thus two out of three seniors have not completed advance directives despite the fact that all of the research sites had conducted programs to educate residents about the importance of having a health care proxy.
- The most important predictors of having an advance directive are attitudes toward end-of-life decision making, living alone and advance directive literacy.
- People trust their families to make health care decisions for them.
- When asked whom they trust the most to make medical decisions for them, the vast majority (79%) mentioned a spouse or other family member.
- Those without a health care proxy were more than twice as likely to mention their spouse.
- Only 17 percent mentioned their physi-

cian.

- Many were confused about advance directive documents and New York State instructions.
- More than half (55%) of respondents have difficulty grasping the facts about NYS law pertaining to end-of-life treatment decisions.
- More than half indicated they believed family decision making was legal in NYS without a designated health care proxy even after reading a statement that the law states otherwise. Another twenty percent were not sure.
- More than a third do not understand that the family cannot make decisions if a non-family member is the designated decision maker.
- Even after reading a definition of the health care proxy, only 28 percent indicated a clear understanding of this document.
- A standardized assessment of document literacy showed that only six percent of respondents understood the NYS instructions for completing a proxy form. ■

*Lois Steinberg, Ph.D., M.P.S. devoted two HAP internships to the Family Health Care*

*Decision Act, the first at NYPIRG and the second as coordinator of a coalition of forty organizations that support passage of this bill in New York State. Together with Pat Banta and Marsha Hurst, Lois wrote the proposal for the literacy study that resulted in project funding from Pfizer, Inc. She is now conducting focus groups on palliative care for FRIA (Friends and Relatives of Institutionalized Aged) and the National Alliance for Caregivers, working under a grant from The Fan Fox & Leslie R. Samuels Foundation.*

*Pat Banta, B.S.N., M.A. (HAP 1999), is Program Analyst at the New York City Regional Office of the Federal Department of Health and Human Services, Office of Inspector General, Office of Evaluation and Inspections. Her office conducts research into Medicaid and Medicare. Before completing the HAP program, Pat was a critical care nurse for 28 years. Pat is married to a former actor turned accountant/fiduciary. Their two grown sons both live in the city; one is an artist and the other an engineer.*

*Marsha Hurst, Ph.D. is Director of the Health Advocacy Program.*

## "Changing Social Policy" Accepted for Publication

Marty Mancuso, director of grassroots advocacy for the New England division of the American Cancer Society, received her M.A. in Health Advocacy in 2000. For her final internship, Marty did a fascinating capstone project on the fight to get adequate insurance reimbursement for ostomy supplies in the state of Connecticut. With two co-authors, Marty wrote a paper on the successful effort, "Changing Social Policy: Grassroots to Legislation," which has been submitted for publication in the *Journal of Wound, Ostomy and Continence Nursing*. The abstract follows.

*Changing Social Policy: Grassroots to Legislation*, by Liz Lemiska, R.N., B.S.N., C.W.O.C.N., Eileen M. McCann, R.N., B.S.N., C.W.O.C.N., and Margaret Mancuso, M.A.

*Never doubt that a small group of thoughtful citizens can change the world: indeed it is the only thing that ever does.*

— Margaret Meade

Healthcare in the United States has evolved into a multimillion-dollar business. As the healthcare industry has grown, so too has government regulation and involvement. As both insurers and patients vie to get the most for their healthcare dollars, federal and state governments attempt to mediate, prevent fraud and abuse, and protect all parties involved. Consumers feel the effects of this "tug of war" in the form of higher co-payments, premiums, out-of-pocket costs and often, denial of coverage. This denial of coverage sparked a very successful grassroots effort to stop commercial insurers in the state of Connecticut from defining ostomy supplies as cosmetic and thus denying reimbursement. A tremendous amount of collaboration between Connecticut Wound Ostomy and Continence (WOC) nurses, state legislators, local American Cancer Society advocates, United Ostomy Association (UOA) chapter members,

and health care providers resulted in a powerful mobilization and support for House Bill (HB) Number (No.)5120, which went beyond defining ostomy supplies as medically necessary, but also set a minimum rate for reimbursement. Social policy changed, improving the lives of Connecticut citizens with an ostomy. While many people fear they do not have the power to make necessary changes in government, this experience proved otherwise. The collaboration that occurred was patient advocacy at its best. This article describes the process that allowed this successful collaboration to take place to hopefully inspire others to get involved with patient advocacy through political involvement. It is the intention of this work to capture the essence of dedication of a grassroots campaign involving a small group of well-organized, highly focused participants who were responsible for changing public health care policy in the state of Connecticut. ■

# A First Year Student's Perspective

by Donna Gentry

There are many reasons why people come to the Health Advocacy program at Sarah Lawrence College; everybody here has his or her own story. I believe that part of the strength and beauty of the program is how everybody's story is important and how everybody's story grows and changes throughout their time here.

When I entered the Health Advocacy program a year ago, I came with some concrete reasons but also with some rather vague ideas about how those reasons would become reality. I had been laid off from my job of ten years (not in the health care field) and knew I needed more education in order to obtain a better, more interesting job. I also knew that the health care system was complicated and difficult to maneuver and wanted, somehow, to make it easier for people. The Health Advocacy program seemed to fit both my needs and my interests. I had no idea what awaited me that first year.

It had been years since I had been in school and the academic setting was quite intimidating, yet the challenge was

exciting and stimulating. In each class, I tried to grasp the basic ideas of the theoretical approach and apply those ideas to what I knew of the world. Yet through the first year, I was almost overwhelmed by the amount of work and studying required. The pace was fast, with each week building on the previous week's work. Struggling to keep up and somehow filter all the readings and discussions into a meaningful and understandable statement was horrendously difficult in some cases. Anybody who's written weekly worksheets knows what I mean! I often found it difficult to keep track of the ideas and reasons that had driven me back to school.

I was distressed at the end of the first semester. As I look back, it was probably the most difficult four months I've had—academically, financially and emotionally. I was stressed, tired, ill, and unsure of myself when December came around and was simply glad to have a break. I felt a lack of cohesiveness in my studies and had no real feeling that I'd done what was expected of me in the semester.

In the spring, some of the confusion remained. While I felt I had accomplished quite a lot just by making it

through the fall, I still had some problems with expectations; my teachers' expectations of me, my expectations of class, and my expectations of how the classes would intersect to create a cohesive program.

I believe that in the future, more discussions with professors might be helpful, so that students don't feel so much at sea. I felt, and I believe that several of my classmates did as well, that while graduate school is supposed to be challenging, in several cases we weren't given quite as much guidance as we would have liked or appreciated. I'm sure that some of that is my fault; I didn't ask for much. In at least one instance, meetings didn't help; I remained confused. It's difficult to provide appropriate structure in an environment like Sarah Lawrence, where so much of the learning is self-directed; but when a student isn't focused on anything in particular, self-direction looks a lot like desperate flailing.

At the end of the first year, I was thrilled that I had made it through, and done well, but my original motivation seemed to have been lost in a hazy mist of academia. I still wasn't sure what a health advocate did in the real world. I needed to somehow connect the theory to practice. The turning point, for me, was the experience of my first internship.

I was unsure of what I wanted to accomplish with an internship. Truthfully, I just wanted to do one, to get it over with, but I did want it to be a meaningful experience. I didn't want to waste the opportunity of having real world experience in the health care field. I chose to work with a community collaborative that focused on childhood issues: the Early Childhood Initiative (ECI). It's a group in Yonkers that is comprised of community-based organizations focused on children—the library system, local hospitals, social service groups and city organizations, etc. This group comes together with a mission and vision that each child in Yonkers will be born healthy, be nurtured, be in a supportive family and community and enter school ready to learn. Each member of the group has its own activities, but also as a group the Initiative runs its own projects. One of them is their recently published *Data Book* (see page 16), which is the first publication in Yonkers to

## EXCITING NEW FELLOWSHIP ANNOUNCED

### Porrath to Fund Cancer Patient Advocate

We are pleased to announce an exciting new fellowship in cancer patient advocacy, to be funded by The Porrath Foundation for Patient Advocacy (PFPA) in Beverly Hills, CA. The fellowship will be awarded annually to a Sarah Lawrence College Health Advocacy graduate student interested in a career in cancer advocacy.

The express purpose of The Porrath Fellowship for Patient Advocacy is to train the student to become a cancer patient advocate and deliver advocacy services to individual patients and their caregivers. The \$10,000 in fellowship support will enable a student interested in direct cancer advocacy to take advantage of a learning experience that is not a paid internship and that s/he might otherwise have to forgo for financial reasons. The fellowship recipient will be selected by a committee of HAP faculty, alumnae/i, and a professional cancer ad-

vocate, with the participation of an active member of the Foundation.

The PFPA calls itself a "voice for personal advocacy services for cancer patients and caregivers" and aims to enable cancer patients to understand the information and options presented to them, participate proactively in the process, and make effective choices and medical decisions.

PFPA was founded by Saar A. Porrath, M.D. and his wife, Toni Bernay, Ph.D, a psychologist. Dr. Porrath was an internationally renowned breast oncologist, radiation therapist, consultant, author and speaker. He also became a patient when he was diagnosed with cancer (plasma cell leukemia). His personal experiences during his last two years of life were the catalyst for this project.

For more information about the Porrath Fellowship, email Marsha Hurst at mhurst@slc.edu.



# A First Year Student's Perspective

*Continued from page 14*

gather city data in one place: health information, school statistics, child care slots, library programs, crime data, neighborhood information, as well as information about strengthening families and nurturing children. The ECI also hosts a Family Day each November, a day full of activities and fun and devoted to the appreciation of families.

My mentor during this internship was Rachel Grob, a graduate of this program as well as an instructor here, and she understands the direction an intern needs in order to have a meaningful experience. I've been to meetings where my input has been appreciated. I was involved in substantive ways with both the *Data Book* and Family Day. I did some minor editing and proofreading and helped choose pictures for the *Data Book*. Most of all I've sat back and watched and learned how a community collaborative functions in order to remain true to its stated vision and reach its goals. It's been an interesting study of cooperation between community groups and how the groups maintain and foster a relationship with a political power structure that doesn't always agree with and/or support their efforts.

The most meaningful part of this internship has been my involvement in a project focused on utilization of medical homes for children in Yonkers. This project arose from the wish of the ECI to have pediatricians involved with the ECI, and the idea of medical homes seemed appropriate. A "medical home," as defined by the American Academy of Pediatrics, is medical care that is "accessible, family centered, continuous, comprehensive, coordinated, compassionate and culturally competent." The hypothesis was that there was an underutilization of medical homes for children in Yonkers, but data was needed to either support or refute that hypothesis. So the project has begun by gathering and analyzing data on emergency room visits of children aged 0-5 in the three hospitals in Yonkers. The hope is to use the data as a starting point for an educational model to help teach people how important it is to choose a pediatrician for their children and why it's important to use the pediatrician instead of the emergency room. I wrote letters requesting information and designed forms to gather the information,

and took some beginning steps toward creating a program. And as suddenly as that, I became involved in something that has the potential to affect people in a systemic and meaningful way.

Whether this project finds funding and really has an impact is yet to be seen. Yet the importance of the project to me seems to go to the heart of my educational experience at Sarah Lawrence. I came with the idea of some sort of direct service, helping people one on one. Creating policy or a program that could help people in a larger way seemed beyond me and my abilities. To me, policy makers were "those people." I didn't know who those people were, but they certainly weren't people like me. I'm intelligent and I care about people, but I couldn't see myself as a creator or an analyzer of policy or programs. I realized, by virtue of the real-world experience of this internship, that not only could I help people one on one, but I could help in a larger, more policy-oriented way, by becoming one of "those people."

My classes and training in the program had created an awareness of both the importance of creating policy and the effect of a policy's impact on people. This program is in the unusual position of being concerned with both. My internship put those academic theories into the practical world and helped me learn to apply them effectively. I realized that the

avenue I want to pursue will somehow have to include health policy and patient education.

Somehow, through that mist of readings, worksheets, research papers, class discussions and peer discussions, I had changed not my abilities, but my perception of my abilities. My confidence grew and that growth altered my ideas about my future.

I would probably have achieved some of the same self-awareness and growth in any good graduate program, but I'm not sure I would have discovered the focus I now have. And I'm not sure if another program would have cared about my personal growth as long as I paid my tuition. I do know if I had chosen differently, the weekly worksheet stress would have been avoided! In any case, come this spring, I'll graduate (hopefully!) I'll have to go back to the real world and find a spot for myself, one that I hope will take advantage of the skills I've acquired and the abilities I've nurtured here. I think my time here was well spent. ■

*Donna Gentry graduated the University of Texas at Arlington and will receive her M.A. in health advocacy from SLC this September. Donna is looking forward to jump-starting her lapsed exercise program, preparing for another graduation (her son's, from kindergarten), and eventually to joining the workforce.*

## HAP IN CUBA IN 2002

A group of health advocacy students, faculty and alumni/ae are planning a one-week trip to Cuba, January 5-13, 2002. The goal of the trip is to learn about health care in Cuba. HAP student Cathey Bienkowski has been to Cuba with a former Peace Corps volunteer group interested in health care and is helping to plan this exciting trip.

Sarah Lawrence College has an undergraduate student program in affiliation with the University of Havana, and this year there are SLC undergraduates studying in Havana for the first time. The HAP trip will be a more professional learning experience, but we are benefiting from the relationship already developed between the University of Havana

and SLC. We will be working through an organization called MEDICC that has planned and arranged educational trips for other health professionals in the US.

Participants will be housed in the graduate dorms of the National School of Public Health in Havana. Fulltime translators will be on hand to facilitate visits to hospitals, nursing homes, domestic violence and substance abuse programs, an AIDS sanitarium, a maternity clinic, a mental health facility, and various alternative medicine and primary care sites.

To check whether it is still possible to join this trip, email Marsha Hurst at [mhurst@slc.edu](mailto:mhurst@slc.edu).



# Yonkers EIC Publishes Beautiful *Data Book*

By Deborah Hornstra

It's a gorgeous book that wouldn't look out of place on your coffee table. Printed on high-quality paper, bound to lay flat, and bursting with dynamic graphics and colorful pictures of beautiful children and their beaming parents, the *Yonkers Early Childhood Data Book 2000* is eye candy that will bring a smile to your face. But in addition to its considerable aesthetic appeal, the book also contains every fact and figure one could want to know about the state of early childhood in New York's fourth largest city. It's designed specifically to help local service providers create better programs for children from birth to age 3, so Yonkers children's advocates will want to keep their copy in the office. But the book also provides plenty of information of value to other Westchester-based advocates, and will interest advocates from outside the area as the first book of its kind ever created for any city in the United States. It's an inspirational example of what can be done by that rarest of entities, a coalition of highly motivated and well coordinated community groups (see ordering information below).

HA II instructor Rachel Grob (HAP 1992) spearheaded the *Early Childhood Data Book* project, which was funded by a grant from the Surdna Foundation. In her usual incarnation, Rachel is director of policy analysis and planning for the Julia Dyckman Andrus Memorial, the private not-for-profit children's and family services agency in Yonkers, and coordinator of its Early Childhood Initiative (ECI). But for the more than two years it took to put together the *Data Book*, Rachel found herself assuming a new role, acting as the consummate point person as she carefully gathered and sorted out the ideas and comments of more than fifty public and private

agencies and one hundred individual contributors to the final product. In addition to using quantitative data of various kinds, *Data Book* researchers spoke with over 200 Yonkers parents in focus groups and interviews, asking them what they needed to raise their children. These qualitative data add a compelling personal dimension to the book, giving real voice to what might have been a collection of faceless tables and charts.

Throughout the project, there was a

ately negative impact on children. The *Data Book* calls the severe lack of quality child care one of the top three children's issues facing Yonkers, with an incredible 80% of survey respondents reporting a shortage. Other key children's issues are very poor rates of prenatal care and high rates of low birth weight.

But the good news is more compelling, and that's what Rachel and her colleagues wisely chose to emphasize. "Something special is going on in Yonkers," she says. "Something has coalesced around the ECI and people are excited. This is a community-based, collaborative group that's been going for three years now and we are getting stronger every year."

What are people actually doing with the *Data Book*? "People are using it for background," explains Rachel. "They're using both the data and the qualitative statements of people saying what they need, which mirror the data. Groups are also using it for strategic planning, taking it to their subcommittees and on

their retreats. And it's been used to generate more interest in Yonkers and the ECI from foundations and consulting groups who want to use the book as a model for communities that wish to do this kind of assessment."

"The *Data Book* shows how far ahead of other communities Yonkers is," continues Grob, "and what a really good place it can be for families and young children. By emphasizing the positive, we are engaging the power of the self-fulfilling prophecy. People naturally have pride in their strengths. When you publicize those, their sense of pride grows stronger and their feelings of capability and ownership are augmented. This feeds back into the cycle of progress."

The publication of the *Data Book* was featured in both the local newspaper, the

## YONKERS EARLY CHILDHOOD DATA BOOK 2000



### Building on Our Strengths Meeting Our Challenges

determined effort to accentuate the positive. "It was one of our goals throughout to focus on strengths. We went through a lot of revision and rewriting to make sure we were capturing what's going well in Yonkers as well as what challenges remain," explains Rachel with justifiable pride in her team's results. "We even went so far as to reverse the subtitle of the book, which was originally 'Meeting our challenges, building on our strengths.' We thought it was important to mention the strengths first, to commend the good things that are happening, and by so doing increase the commitment, energy, and optimism of all who are working toward the ECI's vision for a healthier Yonkers."

As a large, multicultural city, Yonkers is of course not without its problems, many of which have a disproportion-

# HAP Student Placements, 2000-2001

As usual, recent student internships have reflected the full range of health advocacy roles and positions. Students have interned as patient advocates in hospital settings in New York, Connecticut and Massachusetts, including the following hospitals:

Massachusetts General Hospital (Barbara Winrich); Memorial Sloan Kettering Cancer Center (Carol Fleming-Huskisson); St. Vincent's Hospital and Medical Center (Monica Malakar); Yale New Haven Hospital (Lois Booth); Hospital for Special Surgery (Linda Twomey); White Plains Hospital (Linda Twomey); Mount Sinai Medical Center (Sheila Drogy); New York-Presbyterian Hospital, Weill Cornell Medical Center (Tasha Smith)

Laura Weil, Director of Patient Representatives at Beth Israel Medical Center and part of the Health Advocacy core teaching team, is faculty advisor for all of the students interning in patient representative departments. Joining us this spring as a faculty field placement advisor is Constance Peterson, who developed and runs the patient representative program in the Emergency Department at New York-Presbyterian Hospital, Weill Cornell Medical Center. She is working with three students interning in emergency departments, Lucinda Watson at Greenwich Hospital, Ethlouse Banks at Lawrence Hospital and Barbara Winrich, who is working with Constance at Weill Cornell.

Rachel Grob, Jane Nusbaum and Marsha Hurst have been the faculty advisors for students interning in a wide

range of other health advocacy placements. Some have been in hospital settings but not in patient representative roles. Lee Furman interned in a new United Hospital Fund-sponsored Caregiver Institute at Mount Sinai Hospital and Medical Center. Barbara Winrich worked as a patient advocate under the supervision of the Women's Health Clinical Coordinator at the cancer center of University of Massachusetts Memorial Medical Center. Irene Ferko is at Westchester Medical Center working under HAP graduate Rachel Godfrey in the pet therapy program and on a project to develop the multicultural resources of the Center.

Some of our non-hospital internship settings are placements recommended by past students. Isela Chavarria is continuing our long association with the March of Dimes Resource Center. Monica Malakar is doing her last placement at FECS, a large behavioral health agency, where she is learning about quality assurance and human resources training. Betti Weimersheimer interned at the Office of the Inspector General (DHHS) where Pat Banta (HA '99) is now working. Fadya Casseus spent the summer at the Children's Defense Fund, and Rachel Grob continues to supervise interns working with the Early Childhood Initiative at Julia Dyckman Andrus Memorial. Allison Sole wrote for Managed Care Interface this past summer, following an internship that had been piloted by a Melissa Haller (HA '00).

Some internships, however, are in new settings and new advocacy arenas.

Mirsada Pasalic is continuing her interest in assisted living and care management by combining internship work in an assisted living setting with interviews with care managers who work with various agencies-as well as independently-in the New York area. Two students have interned in managed care organizations, Donna Gentry at Health Source in Westchester and Monica Herrera at Regents Blue Cross Blue Shield of Oregon. Desiree McDougall and Anu Philip interned with different programs run out of the Port Chester Carver Center, which serves a large Hispanic, and heavily immigrant community.

Jane Nadel is planning health curriculum and teaching woman inmates in Connecticut. Also working in an education-related internship, Liz Masek is working with a program called GO GIRLS, which is a school-based eating disorders prevention program for early adolescent girls. Susan Slosberg did her last internship working on a resource book for Castle Connolly Medical Ltd under the supervision of HAP graduate, Arline Lane. Allison Sole is our first intern at Consumers Union, working on the early stages of a web credibility project, with her focus being on the ethics of ehealth sites. Jennifer Johnson interned last summer on a research project on AZT and pregnancy at the Columbia's Mailman School of Public Health (under the NYC Health Research Training Program), and has been interning this spring with the Director of Programs at the SLE-Lupus Foundation of New York. Finally, Jody Harris has continued her interest in cultural sensitivity in health care delivery by working on a manual for the upcoming (May 23) conference, "Who Will Decide for You?: Advance Directives, A Cross-Cultural Perspective" organized by the Greater Southern Brooklyn Health Coalition's Center for Immigrant Choice.

Being Sarah Lawrence College, there are always exceptions and individualized study. Marty Mancuso did a magnificent capstone project, a case study of legislative advocacy, for her last placement (see "Changing Social Policy" on page 13), and Cathey Bienkowski did a health field trip to Cuba which she is combining with a course at SLC and research and workshop preparation for our health advocacy Cuba trip in January 2002 (see "HAP in Cuba in 2002" on page 15). ■

## EIC Publishes Beautiful *Data Book*

*Continued from page 16*

*Journal News*, and the Westchester edition of the *New York Times*. The *Journal News* called the *Data Book* a "brilliant" effort that "spells out clearly what children need and should have, and what families can do to ensure their youngsters have a proper start in life." The *New York Times* pointed out that getting so many disparate groups to work together to create the book was an accomplishment in itself, and noted that the book's "basic information dealing with children's developmental needs is easily transferable to communities across the county and across the country."

The *Data Book* was formally released last January at a special event at Andrus Memorial; SLC president Michele Myers was the keynote speaker. In attendance were various representatives of state, county and municipal government. ■

The Yonkers Early Childhood Data Book is available to policymakers and planners, parents, civil and religious leaders, academics, journalists, and the community at large. The price is \$15 per copy plus postage. For more information, call Rachel at 914-965-3700, ext. 1282, or send her an email at [jdamrng@andruschildren.org](mailto:jdamrng@andruschildren.org).

# Director's Desk

Late in April Arthur Frank, Professor of Sociology from the University of Calgary, was our guest in the Health Advocacy Program. Art's main work has been on illness narratives, his own in *The Will of the Body*, and the illness narrative as a "story" that helps us understand the experience of illness in *The Wounded Storyteller*. At the end of Art's seminar with the Health Advocacy class he talked about how he understood the relationship between comprehending the "story" of illness and being an advocate.

We can understand the story of illness as a "restitution" story, one in which illness begets diagnosis begets treatment begets wellness. This story is very focused, goal-oriented and complete. The advocate's role implied by the restitution story is also very focused: get more people diagnosed, earlier, more access to treatment, more effective treatment, more funding for research, more of the good things that bring successful endings to illness narratives.

Or we can understand the story of illness as either a "chaos" story, in which the narrator cannot make any sense of her illness, or a "quest" story, in which the storyteller experiencing illness is on a search for the meaning of the experience, as well as for the cure for the disease itself. If the narrative of illness is understood in this more complex and less complete way, the advocate's role is also broader. As advocates we need to truly hear the illness narrative, be willing to experience a transformation in ourselves when we empathize with the suffering of another, and be prepared to advocate for change in any or all of the institutions and systems that provide care for the sick and dying in our society. The reason, said Art, for an advocate to get an education grounded in the liberal arts is to be able to truly "witness" the illness narrative and move from that narrative into the many and interrelated arenas of advocacy to which the story may lead.

This distinction between the "tunnel vision" school of advocacy, which is very focused, but very narrow, and the broader understanding of the advocacy role has been on my mind recently. The Sarah Lawrence master's program in health advocacy is deliberately grounded in the liberal arts, with a commitment to a broad and interdisciplinary

education for people who intend to advocate for patients, families, consumers and the silent sick or unheard ill in society. We see advocacy not as one task, nor as one position, but as a complex of roles that we can play in many different actual positions in healthcare. Advocacy is a perspective, a way of understanding and a call to action.

This difference was brought home recently by the contrast between two events I attended: the National Breast Cancer Coalition's ([www.natlbcc.org](http://www.natlbcc.org)) annual advocacy conference and a presentation to the Health Advocacy II class by Maggie Hoffman, co-founder of Project DOCC, a training program for doctors that focuses on the impact of chronic illness and/or disability on families. NBCC is a very effective national advocacy group that has become a major voice for women by focusing on one disease with very long tentacles. NBCC uses the force of the restitution narratives of thousands of women with breast cancer to target specific policy priorities and lobby for more research and better treatment. Project DOCC is a small, locally-based grassroots advocacy group with a goal that is more of a concept than a specific target: they aim to shift the thinking of medical professionals from the hospital to the home, from specific diseases to whole individuals, from individual patients to whole families, from medical interventions to life supports. The stories of parents of chronically ill and/or disabled children are "messy," and Project DOCC tries to teach physicians to really hear a quest or even a chaos narrative in these non-linear accounts.

This question of which story we hear and how it frames our advocacy roles raises a core issue in the movement to credential or "certify" patient advocates. Spelling out the competencies required in a particular advocacy role or position is a way to ensure that an advocate is qualified and knowledgeable, but it also implies that the knowledge needed in a particular role or position has definable boundaries. Perhaps we need to think of a professional health advocate as having three layers of "credentials." One layer would encompass the broadest vision with the most depth. It would consist of analytical thinking, of wise judg-



ment, of clear problem-solving — and underpinning all this would be the ability to "witness," to truly hear the patient's narrative.

The second layer would consist of the competencies an advocate needs in any setting — for direct advocacy, for example, these would include ensuring rights, providing "navigation" assistance, mediating, facilitating, communicating, connecting, coordinating, educating, supporting and so forth. The third layer would comprise competencies — information-based knowledge areas — specific to certain kinds of positions, for example, an acute care hospital, a community health setting, a voluntary association. I am now involved in efforts to think through some of these issues and look at competencies in two different areas of advocacy. The New York State Society for Healthcare Consumer Advocacy ([www.nyshca.org](http://www.nyshca.org)) is drafting core competencies for the patient advocate (see page 19). And, encouraged by the new opportunities for patient advocates in other settings, and spurred on by the exciting new fellowship opportunity for a health advocacy student (see page 15), I asked a group of cancer advocates\* to help craft a description of the role of the patient advocate in a clinical cancer care setting.

As I continue work on this important area of professional development I am mindful of some of the pitfalls of this approach. We must recognize that our own concern with competencies is part of a larger societal emphasis on standardization and credentialing. After 125 years, even the American Public Health Association is moving toward public health credentialing. We read about this

\*Karleen Habin, RN, Clinical Coordinator for The Center for Women's Health's Comprehensive Breast Center at University of Massachusetts Memorial Medical Center, Barbara Belhumeur and Marty Mancuso, HA '00 and Barbara Winrich, HA 01, who will be the first professional advocate hired in the U Mass Breast Center.

# Core Competencies Document Authors Seek Input

For some time now, health advocates have considered the notion of credentialing as a means of indicating mastery of certain core competencies needed to do advocacy work. HAP director Marsha Hurst has been working with Ruby Greene, president of New York-based RHG Consulting Services, to develop a document that defines such core competencies and might be used as a basis for credentialing efforts.

Marsha and Ruby, formerly a patient representative at Long Island College Hospital, have drawn up an extensive list of competencies the health advocate should possess. Among them are knowledge of bioethical theories and applications, knowledge of relevant regulations, legislations, and professional and institutional standards, conflict manage-

ment/dispute mediation skills, and cultural and linguistic sensitivity.

Other essential competencies the two have identified are communication skills, the ability to be a health educator, management skills, and problem identification and solving skills. The draft document also calls for advocates to have an understanding of the experience of illness from the patient's perspective, the conditions that affect a community, and current payment issues in health care. In all the authors have identified nineteen broad categories of competencies; many of these are broken down further into subcategories.

Marsha and Ruby will present their paper on core competencies to the membership of the New York Society for Healthcare Consumer Advocacy at the

group's annual meeting on June 8, 2001. Members in attendance will have an opportunity to review the draft document and to propose revisions. HA Bulletin readers are also invited to submit their comments on core competencies and the credentialing process. To review a copy of the draft document, email Marsha at mhurst@slc.edu. ■

## HAP Speakers 2000-2001

The Health Advocacy Program continues its tradition of hosting thought-provoking extracurricular lectures and discussions. Featured speakers this past academic year include the following:

Ruby Green, M.P.A., President, RPG Consulting, Inc., spoke on "The Protection of Human Research Subjects in Clinical Research."

Vikram Khanna of State Health Policy Solutions, LLC, addressed "Clinical Trials as a Public Policy Challenge."

"Deafness: Disability or Culture?" was the title of a panel presentation by Abbey Berg, Ph.D., professor of speech & hearing at Pace University; Maryrose McInerney, MA, CCC-A, Director of Audiology Services at HUMC for 20 years; M. Katherine Oelrich, MS, Certified Genetic Counselor, Department of Biology, Gallaudet University; and Sandee Weintraub, parent of a 10-year-old deaf boy and for the past 5 years president of the Alexander Graham Bell Association for the Deaf (NY).

Meg Walsh, CEO of Oncology.com, spoke on the rapidly changing field of ehealth.

Jessica Yu, Oscar winning filmmaker showed and discussed "The Living Museum," a documentary about Creedmor Psychiatric Center. Ms. Yu also visited Marvin Frankel's class to show and discuss "Breathing Lessons," her Oscar winning documentary about Mark O'Brien, poet & journalist, and his life in an iron lung.

Maude Blundell, M.S., Genetic Counselor, Rockefeller University Hospital, discussed "Ethical Issues Within the Mentally Ill Population." ■

## Director's Desk

*Continued from page 18*

movement every day in accounts of the seemingly inexorable march of standardized testing through our school systems. Just as teachers can find it professionally demeaning to teach to the standardized test, so can it be demeaning to health professionals to have their professions reduced to an enumerated list of requisite skills and the knowledge of specific bits of information.

This means that credentialing both raises and lowers the status of a profession. If a profession is identified with certification, and certification rests on specifiable competencies, is it truly a profession, or is it merely a trained workforce? Outlining competencies and using them as a basis for certification can help insure an appropriate standard of knowledge among those who work in a field, but it also enables others to become managers of the work.

If certification is to mean more than a set of specific skills or a bounded body of knowledge, the key is in that first layer of the credential. When the medical profession consolidated, raising its standards and its status (remember the Flexner report of 1910?) the leadership concentrated on education: rather than outline what a doctor should know, they focused on how a doctor should acquire

knowledge. Lawyers and doctors must pass information-based qualifying examinations in order to practice, but they may not sit for those examinations without first being educated in how to understand law or medicine and how to think in that discipline.

It is our goal at Sarah Lawrence to educate health advocates. Their education must be broad enough to enable them to truly hear the illness

narrative and move from that narrative into the many worlds of advocacy in which they can make a difference. The Health Advocacy core course works with a model of concentric circles that illustrate advocacy as change—from its direct impact on the individual patient to its impact on health care provider institutions, communities, social systems and societal values. The health advocate moves between these levels mentally, even when her job is to work in a very targeted area. As we consider how to strengthen the skills that enable us to be expert advocates in a targeted area, I want to make sure we also strengthen that intellectual scope, because advocating in those larger arenas is what gives our profession the potential to change society—for the better.

—Marsha Hurst

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