

HEALTH ADVOCACY BULLETIN

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Letter from the Director

By Laura Weil

The current health care reform debate has created interesting collisions of opinion. Here's one that's perhaps unexpected: there is resistance to finding out which medical treatments actually work best.

There are those who are opposed to engaging in what's being called *comparative effectiveness* research — determining the relative efficacy of treatments and drugs already on the market. Wouldn't we want to know what treatments work best? And wouldn't we want to take advantage of that knowledge to provide people with the best and least dangerous treatments for diseases? Apparently, some people don't think so. Opponents have raised the flags of one-size-fits-all medicine, of limitations on physicians' autonomy to prescribe and of denying patients choices and treatment options. We are so caught up in the American ideal of self-determination that we are threatened by the idea of "standardized care" or that we might be forced to use the best, safest, most effective treatment for a disease. What's at issue here is that the best treatment might sometimes be the cheapest, or the oldest or not the new drug that "Bob's cousin got." We'd rather be swayed by glitzy advertising and bragging rights to "the newest" therapies than by having evidence that determines what actually works best.

The temperature really gets elevated when there's talk about *mandated* rather than recommended clinical guidelines based on comparative effectiveness research, and about *value-based purchasing* that might limit access to exorbitantly expensive treatment that has no greater benefit than less pricey alternatives.

"...the study of the effectiveness of treatments has been grounded (buried?) in the race to find new drugs and devices to bring to market."

But clearly we need to do something to get the U.S. health care system out of the pit of being 37th on the World Health Organization's ranking of overall health care, despite being by far the most expensive system in the world.

Why, one might ask, hasn't comparative effectiveness research been done before? In a system where the provision of health services is driven by market forces, there's been little incentive. This has been exacerbated by the insulation of the consumer from the cost of health care services. In the past, we didn't know what services and drugs actually cost if the fees didn't come out of our personal pockets. Who cared that the new antibiotic cost 20 times more than the generic drug that would have worked just fine?

For the most part, the study of the effectiveness of treatments has been grounded (buried?) in the race to find new drugs and devices to bring to market. The incremental gains in life expectancy or time to disease progression as measured in clinical trials of new patentable treatments has been pretty much the only measure of how well something works. There has been little assessment of whether that extra month gained was worth the misery of toxic effects of devastating chemotherapy. And pharmaceutical clinical trials really have no incentive to publicize that an older drug (maybe off patent, maybe cheaper) is actually better than some new investigational agent. So those results don't necessarily get much press. There's little incentive to study which of the dozens, sometime hundreds, of FDA approved treatments for a particular indication work best. Certainly no drug company would finance such a trial unless it was absolutely sure its drug would win. So effectiveness research has been limited for the most part to those new drugs for which there's a marketable and profitable application.

What we have not done in any systematic way is an evaluation of whether what we call the "standard of care" for many diseases or conditions is really the best way to treat it. That's why "standard of care" in the U.S. varies by geographic region. And certainly there has been little or no research into best treatments for those rare and orphan diseases where the market is just too small to attract the interest of pharmaceutical companies. Now that federal money has been designated via the American Recovery and Reinvestment Act of 2009, comparative effectiveness research will be funded to the tune of \$1.1 billion and we may finally get impartial and concrete information to help us make truly informed decisions about treatment options.

The advocacy piece in all of this is complicated. Health advocates have a macro obligation to consider the best use of limited resources as measured in spendable health care dollars. We also have an obligation on the micro level to protect an individual patient's autonomy and to support the personal choices she or he might make in deciding about treatment options. The

In This Issue

Letter from the Director	1
Letter from the Editor	2
Student Fieldwork.....	3
From Patient to Patient Advocate at Dartmouth-Hitchcock Medical Center ...	3
On the Frontline in the "War of Words" Over Health Care Reform.....	4
African Services Committee and Their Clients: Health-Motivated, Self-Motivated	5
Opportunities for Advocacy with Adolescents	6
Developing Resources for Patients with Breast Cancer	6
On My Way...A LEND Fellow Experience.....	8
HAP Professional Development Series: Social Return on Investment.....	9
Faculty News	10
Using Patient Voice to Construct an Emergency Medicine Clerkship	10
Faculty Profiles: Christobal J. Jacques and Jennifer Buckley	11

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Continued on page 2

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HEALTH ADVOCACY BULLETIN
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Letter from the Editor

By Barbara Robb

This issue of the *Bulletin* focuses on students in the Health Advocacy Program. We've asked some of them to write about their fieldwork experiences. Health care reform, the rights of patients with disabilities, health care for immigrants, adolescent health, HIV/AIDS, breast cancer, hospital care—these are some of the major topics in health care today. And all are fields where HAP students worked in the past year.

Naomi Freundlich found herself in the midst of a "war of words" about health care reform while writing a blog about health

policy for HealthBeat. Celia Bertuzzi was a LEND Fellow, advocating for full inclusion of people with developmental and related disabilities. Shannon Irey worked with the African Services Committee, an organization in Harlem that provides services to immigrants. Ashley Gephart worked for the Adolescent AIDS Program at Montefiore Medical Center. (And Ashley Fletcher worked on HIV/AIDS outreach, testing and education among adolescent women through Project KISS at NewYork-Presbyterian Hospital.) Deborah Teevens Gangl did an internship at the Gillette Breast Cancer Center at Massachusetts

General Hospital and Susan Kingsbury was a patients relations intern at Dartmouth-Hitchcock Medical Center in New Hampshire.

HAP faculty continue their own advocacy work. In this issue, we include an abstract of a presentation by Constance Peterson, who created an emergency medicine clerkship program at NewYork-Presbyterian Hospital. Our newest faculty member, Christobal Jacques, is an advocate for people with HIV/AIDS. Jennifer Buckley has also joined the HAP faculty, as fieldwork coordinator.

HAP Orientation 2009

The Health Advocacy Program welcomed 14 new students in August 2009, as well as 3 who entered the Program last January. Each year during Orientation Week new students hear presentations about the fieldwork experiences of second-year students and recent graduates of the program.



First-year HAP students during program orientation.

www.slc.edu/health_advocacy

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Student Fieldwork

From Patient to Patient Advocate at Dartmouth-Hitchcock Medical Center

By Susan Kingsbury

Lucky me. I got to spend six weeks of a beautiful summer working indoors, full time, for no pay. It was one of the most valuable experiences of my life. In my fieldwork at the Dartmouth-Hitchcock Medical Center, I had a chance to make a difference in people's lives. I gained advocacy experience in the patient relations department and facilitated illness narrative workshops.

Located in The Upper Valley carved by the Connecticut River that runs between New Hampshire and Vermont, Dartmouth-Hitchcock Medical Center (DHMC) includes Mary Hitchcock Memorial Hospital and the outpatient clinic. They share facilities nestled on 225 acres of wooded land in Lebanon, New Hampshire. The hospital, a Level 1 Trauma Center, serves a population of 1.6 million in the New England area. There are walking paths in the woods surrounding the medical complex and a four-story skylighted interior mall at the hub of all services. Pausing in this area, one is likely to observe sotto voce consultations among clinicians, staff walking briskly from task to task, and patients and families awaiting meetings with the shared decision-making team. The environment is light and green, from medical scrubs to the grass and trees visible from the many windows to the interior hall carpet.

DHMC is an exemplary medical center and teaching hospital. Dartmouth College (headed by Jim Yong Kim, M.D., who cofounded Partners in Health with Paul Farmer) and Dartmouth Medical School are just down the road. The Dartmouth Institute for Health Policy & Clinical Practice (representing six key areas of education and initiatives for change, including the Center for Informed Choice) is next door. The hospital is a leader in such practices as shared decision-making and palliative care, and counts Dr. Ira Byock, an authority and author of a number of books on death and dying, as its director of Palliative Medicine. There are major research sites at DHMC, including the Center for Shared Decision-Making and CHaD (Children's Hospital at Dartmouth) and the Borwell and Rubin Research Buildings. Dartmouth Medical School receives more than \$111 million annually in sponsored research.

My introduction to Dartmouth-Hitchcock Medical Center was through the emergency room doors when I needed surgery one mid-

night in the fall of 1998. In the following years, I continued to be seen there for outpatient care. Without exception, the care from critical to follow-up was supportive and compassionate.

An earlier misdiagnosis elsewhere had led to a need for self-advocacy for appropriate attention and treatment. Well into recovery at DHMC, and reflecting on that experience, I mentioned to one of the specialists who treated me that I would like to advocate for other patients. The doctor referred me to the care management team director, who told me that only with credentials could I be a paid patient advocate. My idea lay dormant for a couple of years until I discovered the summer Sarah Lawrence "Writing the Medical Experience" workshop, which introduced me to the Health Advocacy Program. Looking back, it is as though a path opened up in front of me and I followed it.

"...only with credentials could I be a paid patient advocate."

I intended all along to do my summer fieldwork at Dartmouth-Hitchcock. My own experience there, in addition to all I had read and heard, convinced me of its excellence, and I wanted to spend the summer in my home state. It was my hope that applying to an institution that was far from Sarah Lawrence and unfamiliar to the administration, as it had not been a previous fieldwork site, would not be a deterrent. During the course of the Fieldwork Seminar, I expressed my keen interest in Dartmouth and did much of the preparatory footwork myself. During winter break I made a "courtesy call" on the Care Management Team director, Michele Blanchard, and met Lynne Richards at the same time. Making a personal call helped greatly to facilitate my fieldwork placement, I believe. This office at DHMC had never had an intern and wasn't sure what would be asked of them, or who she might be, or what Sarah Lawrence is all about. Reassured, they worked with our fieldwork seminar faculty to iron out the agreement for my participation in the patient services office of care management. Soon after classes ended, my summer advocacy experience began.

As I eased into my summer internship, I became part of a huge community of health advocates. I spent the first day in orientation

(along with 30 other new employees and summer interns) and from then on was accepted as a professional equal. I was entrusted with access to the patient database and offered free rein to explore "anything that will help you during your fieldwork here." I met with the Center for Shared Decision-Making, CHaD and the Boyle Community Pediatric Program, the breast cancer support office and the palliative care coordinator/chaplain at the Norris Cotton Cancer Center, and I accompanied a social worker on a house call to arrange an elderly couple's Medicaid participation.

My supervisor, Lynne Richards, invited me to shadow her daily; I sat in her office while she fielded phone calls, emails and walk-in visits from patients and family members. When the situation involved a concern from an inpatient, we made a "field trip" to the room. Complaints ranged from a rude nurse to dirty sheets to a lost hearing aid to a seriously ill patient's complaint about medical care. My case notes included my observations and assessments. Afterwards Lynne and I discussed the incident: what had been the initial concern and what else was revealed? Had we been able to reassure the patient that steps would be taken toward education, resolution or restitution?

From shadowing I learned the path taken by patient concerns. It begins in the patient relations office and, if the situation is not easily resolved, is directed to the practice coordinator in the appropriate department, and to higher administration and risk management when necessary.

My specific project was to become familiar with the Centers for Medicare and Medicaid Services (CMS) guidelines on dealing with patient complaints and grievances, and to draft a revision of the DHMC policy so that it would be in compliance with the guidelines. I participated in a webinar on the subject and reviewed the websites of other large hospitals and contacted them by telephone to learn about their policy guidelines for matters such as forming a grievance committee.

As an adjunct to the patient relations work, I proposed to the department director two hour-long sessions of illness narrative writing workshops. I was invited to lead them with clinicians from Care Management and Chaplaincy. The outcome of offering a group of health care providers an opportunity

Continued on page 4

Letter from the Director

Continued from page 1

most important piece perhaps is to first advocate for the research that's needed to find out what actually works. The balance between the polar opposites is to preserve options — and let people choose among the best available choices of proven and effective treatments. But first we have to determine what those effective treatments are, without the bias and pressure intrinsic to the marketplace.

Alumnae/i News

Shawna Irish, HAP '07, is the new Alumnae/i Relations Correspondent for the Health Advocacy Program. Please send her news of your work, personal achievements and milestones to be edited and submitted to the Sarah Lawrence Magazine. Feel free to send anything that's happened to you in the last couple of years. Shawna can be reached at shawna.irish@gmail.com

Continued from page 3

to voice their experiences and emotions was successful and touching, and met with heartfelt thanks. From this grew an invitation to engage the Heart-to-Heart monthly cardiac patient group in giving a voice to their experiences. To do this, I returned to DHMC a month after my fieldwork ended.

I found that I had been well prepared for this fieldwork experience by just one year of study at Sarah Lawrence. The reading we do for class is professional and cutting-edge and presents diverse points of view; the writing requires all the intelligence, literary skill, and tenaciousness that we can muster. During six valuable weeks with the competent and engaged people at DHMC, I found I could

hold my own. I heartily agree with Albert Einstein's remark, "Luck favors the prepared mind." The Health Advocacy Program prepared me well.

Susan Kingsbury is a graduate student in the Health Advocacy Program.

On the Frontline in the "War of Words" Over Health Care Reform

By Naomi Freundlich

The battle over health care reform has essentially come down to a "war of words," with opponents and supporters frantically trying to gain the upper hand with the American public. For the last four months I have been immersed in this battle, writing about health policy for HealthBeat, a blog published by The Century Foundation, a progressive think tank. Working on the blog entails researching and writing my own posts and responding to comments from readers, most of whom are very knowledgeable about health care issues. I've also learned how to "post" articles, using blogging software to turn Word documents into a form that can be viewed online.

"...we have found ourselves responding to near weekly attacks on reform..."

As Congress works on hammering out a health plan, Maggie Mahar (the Health Fellow at the foundation) and I have been advocating for fundamental changes in the way health care is structured, delivered and paid for. In addition, we have found ourselves responding to near weekly attacks on reform by conservatives, debunking allegations that reform will bring rationing of care, limited choice of providers, a government "takeover" of medicine and the gutting of Medicare — among other erroneous charges. In the fight for reader opinion, the "blogosphere" has lately been overrun with pundits, many pursuing hidden agendas.

The truth is that very few people will actually read HR 3200, Congress's 1000-plus page bill that lays out the Democrat's version of health reform, but nearly everyone has an opinion about it. How do they form their opinions? Mostly by reading newspapers, magazines, watching short clips on the

evening news or listening to the various TV and radio commentators who spin their favored take on the legislation.

This media frenzy on health care reform has, during Congress's recess, reached a fever pitch. Just when we feel that we have a handle on something — President Obama's support of a public plan option, for example — media reports begin questioning the status quo and making conjectures about how Obama has cut deals with drug companies or insurers and sacrificed aspects of reform we thought were nonnegotiable. It's been a rapid-fire education for me, a print journalist with more than 20 years' experience, in how "spin" and downright gossip get passed along as reporting on many of today's blogs. As a writer and editor for publications like *Business Week* and *The New York Times*, I had always been trained to back up what I wrote with verifiable sources and to dutifully check facts. That is not always the case in the blogosphere.

At HealthBeat, we try very hard to uphold journalistic standards. The impetus behind the blog is Maggie Mahar, a former Senior Editor at *Barron's* and the author of the book *Money-Driven Medicine: The Real Reason Health Care Costs So Much*. Published in 2006, Maggie's book has now been made into a powerful documentary by Alex Gibney, producer of such notable films as *Enron: The Smartest Guys in the Room* and the 2007 Academy Award Winning documentary, *Taxi to the Dark Side*.

I came upon Maggie's blog and other Century Foundation publications on health care while researching a paper for Health Policy. I discovered that they had an official paid internship program, but only for the summer, and I was looking for a spring placement. Nonetheless, I emailed Maggie directly, telling her about my background and saying how informative I had found her

blog. Coincidentally, the Program Associate who had worked with her on health policy had just left. With her film coming out and debate on health care reform heating up, she was very interested in my proposal for an internship.

"...HealthBeat advocates for fundamental changes that will help cut some of the waste, greed and subpar care out of the system."

The message from Maggie's book, her blog and the new film is an important one that strikes at the fundamental problems inherent in the health care industry. In this country, where we spend twice as much as any other country in the world on care, we should be able to claim the mantle of the best health care in the world as well. As we are well aware, that is not the case. With some 46 million Americans uninsured, we lag other developed countries in infant mortality and preventable death, as well as in other key measures of quality. The reasons are complicated, but in *Money-Driven Medicine* Mahar produces a scathing portrait of the vast \$2 trillion health care industry (from the drug industry to for-profit hospitals to device makers and health insurers) where the bottom line and corporate profits have become the supreme goal, rather than excellent medical care. The result: we have a lot more care in this country, but not better care.

Ultimately, our system of profit-motivated medicine has created a dysfunctional system where procedure-driven medicine is rewarded above compassionate care, where patients are offered an excess of the newest, most expensive, but not necessarily the best medicine, and suffer for it. Mahar draws on more

Continued on page 10

African Services Committee and Their Clients: Health-Motivated, Self-Motivated

By Shannon Irely

African Services Committee, through its dedication to immigrant populations in New York City, has established a reliable resource for health education and community partnerships. Located in Harlem, the non-profit began nearly thirty years ago as a collaboration of Ethiopians united to assist fellow immigrants from their own country. Today, the organization provides a plethora of services to 10,000 people each year. Clients are from all over the world, including African countries and the Caribbean; even non-immigrants come to African Services. Additionally, the Committee has developed a sister office located in Addis Ababa, Ethiopia with three HIV and CD-4 testing sites throughout the country. The Harlem office strives to provide free and confidential HIV, STI, TB and pregnancy testing at no cost to the client. African Services' onsite testing allows for close interaction with New York City's most vulnerable populations. African Services offers assistance to those who need it most. Along with testing services, the organization provides counseling and housing assistance to people living with AIDS. Legal aid, English language classes and food pantry services are also available for all walk-in clients.

Another important program the Committee provides is a Hospital Escort once a week for all interested clients. The escort will assist the participant by making their medical appointments and accompanying them to the hospital. Every Hospital Escort introductory session includes HIV/AIDS facts, and all participants are encouraged to get tested on-site at African Services. The service ensures that those in need can seek medical care without fear or reservation. One client says, "Considering my immigrant status, I was treated as an individual and not an alien." Alpha Kassogue is an immigrant from Mali who now heads the Hospital Escort program. He remembers a time when he was new to this country and could not fathom seeking medical care with his limited English language skills and ignorance of the health care system. Today, he deftly moves between his country's native dialects, English and French when speaking with clients, as well as communicating in other languages to explain the health care system.

As a Quality and Advocacy Intern, I performed a needs assessment of a Hospital

Escort session to determine whether the service successfully met the needs of the community. The assessment was commissioned by the AIDS Institute, testimony to the AIDS community's dedication to self-evaluation. I created anonymous surveys and conducted interviews with participants to determine the efficacy of the program. Through this work, I was able to understand just how isolating and confusing an immigrant's experience can be. The appreciation the participants have for the Hospital Escort program and African Services Committee as a whole is best expressed by a client who explained, "These services in this department have restored my confidence and self-esteem."

"Through this work, I was able to understand just how isolated and confusing an immigrant's experience can be."

African Services Committee consistently transforms their projects based on current HIV/AIDS research. After the Center for Disease Control released statistics displaying STI and HIV increases among young adults of high school age in New York City, African Services teamed with the Bronx International School. The program, designed by African Services, selects volunteers to act as student health ambassadors. These students are trained at African Services Committee to talk with their peers, or even loved ones, about the implications of STIs and HIV and encourage them to get tested. These students are predominantly in the most at-risk populations that African Services works with: immigrants from Africa and Latin America.

I was able to be a part of this initiative from conception to execution. Initially, I served as a contact with Bronx International School to develop the program guidelines. I then had the opportunity to visit the school and introduce the students to this valuable resource to help their community. The students' enthusiasm and maturity when speaking about difficult issues concerning STIs and HIV/AIDS was inspiring to witness.

In the past, I have worked with women's groups in South Africa and Ghana discussing the seriousness of HIV/AIDS for themselves and their community. I was able to experience this type of face-to-face work through African Services, yet this

time my function was to aid in the development of new programs to assist these same populations after their immigration.

I was first introduced to African Services by Sarah Lawrence College, through a campus discussion among undergraduate and graduate students with backgrounds and interests in health care. Many of the pre-med students had worked in their testing center, learning to assist with spit tests, which screen for HIV/AIDS through saliva, and other tests. These students spoke highly of their experiences and contact with clients through African Services. I became excited about the prospect of an internship there, and spoke with HAP faculty about it. We contacted their Assistant Program Director, envisioning work in program development. My background in HIV/AIDS prevention and work abroad put me in a position to assist him with creation and management of their health care team.

Working with African Services Committee has given me insight into the complex client-based needs of the HIV/AIDS epidemic, not only abroad but in New York City. I sincerely hope to utilize this perspective into HIV/AIDS research to gain a stronger understanding of successful programs and policies for this population. African Services works to eradicate this epidemic one client at a time; this piecemeal approach is a healthy model for future HIV/AIDS work. The mission of African Services to improve "the health and self-sufficiency of the African community in New York City and beyond" is clearly echoed in client comments. As one client said, "African Services has been my rock in every aspect of my life and my family." Today, the HIV/AIDS sector has brought forth a challenge to serve individuals as well as nations. To deny the people of the epidemic is to deny the power of motivation.

Shannon Irely is a graduate student in the Health Advocacy Program.

Opportunities for Advocacy with Adolescents

By Ashley J. Gephart

For some of us, memories of adolescence are filled with times spent with friends, high-spirited athletic events, school dances and experiments with new hairstyles. But for many New York adolescents, those years are also marked by a diagnosis of HIV. From 2000 to 2006, 3,596 New York adolescents aged 13 to 24 received such a diagnosis. Fourteen percent of males and twelve percent of females had a concurrent HIV/AIDS diagnosis (i.e., the AIDS diagnosis was within 60 days of the HIV diagnosis), indicating an HIV diagnosis late in the course of infection. While the Bronx has the second smallest population of the five boroughs, it disproportionately accounts for roughly 25 percent of all reported cases of adolescent HIV diagnoses.

In response to the number of Bronx adolescents who are diagnosed and living with HIV/AIDS, organizations such as the Adolescent AIDS Program (AAP) at Montefiore Medical Center work tirelessly to address both the personal/behavioral and social/political aspects of the HIV epidemic among local youth. AAP is a leader in the field of HIV/AIDS among adolescents and “serves as a local and national resource for those living with HIV/AIDS; adolescents who are at-risk for HIV infection; healthcare providers who treat adolescents living with or at-risk for HIV infection; and lesbian, gay, bisexual, transgender or questioning adolescents, their families and caregivers.” Additionally, AAP provides clinical assistance to youth diagnosed with HIV, outreach and education to members of the community and clients, and also leads and participates in research aimed at identifying and addressing the factors that result in adolescent HIV transmission.

I found my way to AAP through a friend who was involved in adolescent public

health during her undergraduate studies at New York University. This friend previously worked for AAP and sent the program director an email with my resume attached. I later learned that AAP had already reached its full intern capacity by the time my resume arrived, but the fact that I came highly recommended by my friend earned me an interview. I have always understood that networking is an important aspect of professional life, but this was my first personal experience with its effects. I will continue to make it a point to foster relationships with others inside and outside of the professional world, as you never know where a fabulous collaboration or job opportunity may be hiding.

“...through my internships I am becoming aware of the endless and exciting possibilities for advocacy.”

I was asked to intern at AAP to help with a program called Connect to Protect (C2P), a research program made up of 15 urban sites throughout the U.S. and Puerto Rico. It draws from federal, state and local resources to identify at-risk youth and create a profile of available community resources. Disease and risk rates are compared with availability of services in order to reveal neighborhood strengths and needs. C2P prevention plans can include (but are not limited to) social marketing campaigns, peer outreach, social events, workshops and community capacity building.

Recently, the Bronx C2P coalition identified many root causes for HIV transmission among adolescents, such as low self-esteem, sexual exploitation and elevated rates of sexually transmitted infections, that merit both significant attention and creative and feasible action plans in order to effect change. Currently, coalition members are in the

process of determining the most pressing root cause and developing a new action plan to address the correlating issues affecting Bronx adolescents. As the C2P intern, it will be my duty to eventually lead the resulting subcommittee that will focus on the identified root cause. C2P subcommittee leaders are in charge of setting meeting agendas and determining what structural changes (i.e., changes in programs, policies and practices) would be most effective to deal with the identified root cause. The subcommittee leader and the other coalition members are responsible for completing action steps and ultimately attaining the structural change objective.

While I was initially hired as the C2P intern, I have become involved in a lot of additional activities at AAP. During my interview, I expressed interest in being able to be part of the outreach arm of the organization. As a result, I've gained experience through involvement in outreach events, such as AAP's “Get Tested Week” party and also by participation in trainings, such as an AAP-sponsored LGBTQ issues training for youth service providers.

While I am not entirely sure what aspect of health advocacy I will pursue in the future, through my internships I am becoming more aware of the endless and exciting possibilities for advocacy. Interning at AAP has solidified my interest in health outreach and education and has reinforced the fact that I enjoy working with young people. At each coalition meeting, outreach event and training I meet new people who are doing interesting and crucial work in the field of health advocacy. I am certain that both the exposure and networking will have an impact on my professional future.

Ashley Gephart is a graduate student in the Health Advocacy Program.

class. I put Mass General at the top of my internship list after her fascinating talk. Laura Weil knew of my interest and helped make this opportunity a reality. After two semesters of classes, I was anxious to start this internship. The experience did not disappoint.

My main assignment was to work on the Breast Cancer Resources Guide of Massachusetts. The project, the brainchild of my supervisor Karleen Habin, is a website designed for patients with breast cancer, clinicians, caregivers and family members to

help them better navigate our health care system. This huge undertaking is a collaboration among many public and private programs and is funded by the newly formed Cancer Resource Foundation. My job was to research Massachusetts facilities and the services they offered to breast cancer patients. Consequently, during my tenure I contacted many hospitals and free-standing medical centers and spoke with administra-

Continued on page 7

Developing Resources for Patients with Breast Cancer

Continued from page 6

tors and clinicians about the services they provided, so that I could supplement, edit and update the website with information and links to current resources.

My supervisor and I discussed different ways to present information to promote easy patient access and understanding. In addition, I researched and provided resources for the Media and Support Group sections of the site. One of the more interesting aspects of my project was my work with those support groups. As I learned from a talk by HAP graduate and advocate Maggie Hoffman in our first-year course work, the issue of support is a sensitive one. In researching various resources for breast cancer patients I discovered valuable information on different support groups, how to choose a group and what may be right for the individual patient. As a result, I am now armed with a vast amount of information.

With the blessing of my extraordinary supervisor, I was exposed to a myriad of additional advocacy issues. I attended a lecture on Research Participant Education and was able to speak with Enrico Cagliero, MD, the director of the Research Subject Advocate Program at Mass General Hospital. Given my interest in informed consent issues, I spent time researching information regarding patients entering clinical trials. It turns out there is excellent information available to patients at Mass General. The hospital devotes a great deal of time to making sure that patients are well informed, and provides staff with advice on obtaining consent from patients who do not speak English. After my exposure to this important issue, I thought about this area as another excellent advocacy opportunity.

I was able to sit in on a meeting of newly diagnosed cancer patients and was impressed by the care, concern and resources available to these patients and their families. Given freedom to investigate, I observed patients in the resource room. This peaceful area is designed to allow patients a quiet place to relax. It offers puzzles, a knitting corner, computers, massage chairs and a private area just for teenagers, as well as a beautiful garden. I examined the literature available and paid attention to how it was presented to the patients. I also introduced myself to several of the social workers who run the center and asked them about the material, how they selected it, and how they organized it. They use an interesting system with color-coded symbols that allows patients and caregivers to zero in on the books that would be of most help.

Important advocacy issues such as Grant Writing and Ethics were also on my internship radar. Once again, my supervisor proved an excellent resource and provided her perspective on these issues. She applies for many grants and discussed with me several she recently handled. Reviewing those grant applications helped me gain a better understanding of the strategy behind the process.

“...I was exposed to a myriad of additional advocacy issues.”

Ethics issues were also on my list of interests and my internship provided several educational opportunities in this area. Not only was I able to attend tumor board meetings in the Breast Center where treatment issues were discussed, but I was also invited to observe several meetings in the Proton Beam Center at Mass General. Barbara Winrich is involved in several research studies at the center, one of only a handful of such facilities in the country. Despite her frenetic schedule, she was kind enough to introduce me to her advocacy work. With

her help, I was exposed to issues regarding IRB (Institutional Review Board) informed consent, treatment, patient follow-up and confidentiality, as well as ethical issues involved in research studies. I was able to learn a great deal from this extraordinary part of my internship.

One of the most powerful learning opportunities occurred towards the end of my tenure, when I observed a patient undergoing a surgical procedure. From an advocacy point of view, I experienced a moment that I will not soon forget. The surgeon, a powerful figure at the hospital, held the patient's hand until she was asleep. Though the surgeon could have waited until the preparatory details were attended to and walked in when the procedure was about to begin, that was not her style. Instead, she held the patient's hand. This lovely symbolic gesture remains with me as a reminder of what patient care should be.

Deborah Teevens Gangl is a graduate student in the Health Advocacy Program.

Upcoming Events

Monday, October 26 6:00 to 8:00 pm

Sarah Lawrence College, Heimbald Auditorium
Health, Science and Society Health Care Reform Series

**The Devil Is in the Details:
Current Health Care Reform Proposals**

Panel discussion about the current health care reform proposals. Panelists include **Mark Hannay**, Director, Metropolitan New York Health Care for All Campaign; **Rebecca Johnson**, Health Advocacy Program faculty and Founder and Executive Director of Cooperative Economics for Women; and **Mark Schlesinger**, Health Advocacy Program faculty and Professor of Health Policy and a fellow of the Institution for Social and Policy Studies at Yale University. Event is free and open to the public.

Monday, November 30 7:00 pm

Sarah Lawrence College, Heimbald Auditorium
Organized by the Westchester End-of-Life Coalition
and hosted by the Health Advocacy Program

An Evening with Andrea Raynor

Andrea Raynor, hospice chaplain and clergy, shares her experiences serving hospice patients and police, firemen and morgue personnel at Ground Zero following 9/11 and managing her own life after breast cancer diagnosis, as described in her collection of essays, *The Voice that Calls You Home*, in a conversation with journalist Lee Woodruff. The program will be followed by a reception, book sale and signing. Event is free and open to the public. Reservations requested to info@westchesterendoflife.org (subject line: Andrea Raynor Evening).

On My Way...A LEND Fellow Experience

By Celia Bertuzzi

LEND stands for Leadership Education in Neurodevelopmental and related Disabilities. There are 35 LEND Programs in 29 states. In Westchester, the academic home of LEND and the Westchester Institute for Human Development (WIHD) is in the Department of Disability and Human Development at the School of Public Health at New York Medical College in Valhalla. WIHD is one of 67 University Centers for Excellence in Developmental Disabilities (UCEDD). All LEND Programs and UCEDDs are members of AUCD (Association of University Centers on Disabilities), which is a network of interdisciplinary centers advancing policy and practice for individuals with disabilities and their families. The LEND training programs are funded by the Maternal and Child Health Bureau (MCHB) of the Health Resources and Services Administration (HRSA) of the U.S. Department of Health and Human Services.

In my LEND Program, there were 21 LEND Fellows with two trainees from Puerto Rico who participated via long-distance education technology. We were all graduate level professionals, representing many disciplines including assistive technology, family specialists, speech pathology, psychology, psychiatry, nursing, health advocacy, social work, special education, and occupational and physical therapy. The LEND curricula focused on an overview of Neurodevelopmental Disabilities, Interdisciplinary Leadership Seminar and Seminar in Evidence-Based Methods. Courses were taught by staff members who are leaders in their field.

"...we, the people/advocates, are the ones with meaningful power."

I had the opportunity to work with a team of professionals in creating a team project entitled "Supporting Parents with Cognitive Limitations: Practical Tools for Service Providers." This poster presentation was presented to key leaders at the state and federal level in Albany and an abstract has been accepted for presentation at the November 2009 Disability Policy Conference in Washington, D.C. I also presented a PowerPoint presentation, "A Call to Action: The Need for A Disability Aware Education/Moral Implications." This extra project was required in order to receive my certificate in Children with Special Health Care Needs at New York Medical College.

I am confident that advocacy is attainable and is well within reach. As LEND fellows,

several of us attended a Disability Policy Seminar on Capitol Hill in Washington to advocate for full inclusion for people with developmental and related disabilities. I met with Jean Doyle, Legislative Assistant to Nita Lowry, Rep. D-NY and with the Legislative Assistant to Kirsten Gillibrand, Senator, D-NY. I am proud to report that my submission for the Seminar slide show was accepted by Thomas Webb of The Disability Policy Collaboration. This was my first experience meeting with elected officials, public policy experts, disability advocates and legislative staff. It was an inspiring event to represent the LEND Program together with AUCD, UCP, AAIDD, NACDD and The Arc, all promoting full inclusion of people with disabilities.

As a participant at the Summit, I learned that members of Congress, legislators, and policy makers are real people. At first, I was fearful of meeting with members of Congress or legislators, but was reminded that, we, the people/advocates, are the ones with meaningful power. I learned that legislators enjoy meeting with their constituents and really want to hear our views, concerns and life stories. I felt I had so many stories to share that could make an impact — I only wished I had more time.

I witnessed the strength of a group with one voice discussing key public policy issues that have great impact, such as the Developmental Disabilities Act, Health Care and Long Term Services Reform and Employment and Housing issues. I will share my positive experience with families who have children with special needs, in the hope of empowering them as self-advocates. Attending the Summit and listening to the concerns of people living with developmental and related disabilities and their families helped give me practical knowledge.

I envision going back to the Hill in my future as a leader, as I am no longer fearful. I am honest and steadfast in my views promoting full inclusion of people with developmental and related disabilities and look forward to the next opportunity to promote interdisciplinary education for health care providers and promote the unarguable need for long-term supports and services for children with developmental and related disabilities and families. Advocacy and policy



Celia Bertuzzi and fellow LEND trainees on Capitol Hill before their meeting with legislative assistants.

can be accomplished as interdisciplinary collaboration moves forward through research and education, and LEND prepared me to take the next step.

My LEND training gave me the confidence to start my own program in the NICU at Montefiore Medical Center. It is called NICU PEP, A Program Empowering Parents. It is well documented that parents who have infants in a neonatal intensive care unit experience enormous amounts of stress and anxiety. Parents feel overwhelmed by the experience and feel unprepared for discharge. Education with an emphasis on self-advocacy can help parents understand the vital role they play as primary caregivers. The objectives and goals of this program are to inform parents about core issues of prematurity and gain insight and knowledge about the available supports and services their babies will need to optimize their growth and development; to help parents understand the significance of empowerment and advocacy for their child as they navigate the health care system; and to encourage parents to become active participants in the Parent Empowering Program, fostering their confidence as they begin to partner with health care providers.

Continued on page 11

HAP Professional Development Series: Social Return on Investment

By Cipora Moskowitz

Social entrepreneurship was the compelling focus of the HAP Professional Development Series program held on June 19th in the Campbell Sports Center Conference Room. Rebecca Johnson, HAP faculty and Organizational and Fund Development Consultant, introduced the panel of speakers, who talked about their professional endeavors to find resourceful solutions to social problems and create positive changes in their communities and beyond.

Social entrepreneurship refers to activities that employ business principles to create social change and create initiatives that successfully respond to social issues. The activities are generally replicable, sustainable and affect more than one sector of a social system. Social enterprise may be funded entirely or in part by philanthropy, but more often refers to entrepreneurs who want to create a business that is self-sustaining. The primary goal of social entrepreneurship is social good, but business profits are often part of the equation.

Panel member and HAP alumna Jane Nyce, Executive Director of Staying Put in New Canaan, described her organization as providing social services to "keep you safe and confident in your home as you age." An aging-in-place initiative akin in many respects to the Beacon Hill model, Staying Put in New Canaan uses a blend of membership fees and state and federal support to provide services for older town residents, ranging from transportation to a medical appointment to home maintenance referrals to tickets to a Broadway show. Members volunteer and barter their time and skills with other members, helping to lower program costs and providing an added social return to the volunteers. An example of social entrepreneurship, this organization uses a business model to collect annual membership fees from members to sustain the administrative structure that manages a network of unbilled services to seniors.

HAP alumna Lois Steinberg, Director of Westchester Programs for the Medicare Rights Center, described how the organization provides information and advocacy services to Medicare recipients, and highlighted the importance of synergies between partners as a means of sustaining local social services. Similarly, Sheila

Reynertson (another HAP alumna) of MergerWatch Project explained, we are "not reinventing the wheel." Rather, to survive, we must look toward partnerships and regional alliances, utilize existing resources and collaborate with other community groups. MergerWatch specifically works to either stop hospital mergers or counter any negative impact such mergers might have on communities that are served by the involved institutions.

"...creativity with resources, both financial and technological, drives social innovation."

The keynote speaker, Founder and CEO of Sustainable Health Enterprises (SHE) Elizabeth Sharpf, presented the idea that "charitable efforts alone are not enough to address the breadth and complexity of socio-economic and health problems that exist in developing countries." Sharpf's work has been recognized by Echoing Green (www.echoinggreen.org), which honored her as one of its Fellows for 2008 in the area of health and community development. She is also the inaugural recipient of the 2009 Harvard Business School's Social Entrepreneurship Fellowship, which noted that "SHE is a platform for starting businesses that use innovative, market-based approaches to tackle socio-economic and public health problems in developing countries."

Her involvement began when she volunteered as a coach of a girl's soccer team in Rwanda. She found that often she did not have enough players to comprise a team for a scheduled match. Sharpf was shocked to learn that her players did not show up for games while they were menstruating. After surveying 500 girls, she discovered that they could not afford to purchase sanitary pads. Sharpf extrapolated that these girls were also missing school for significant periods of time, and that their potential for social and economic advancement could be seriously affected by their school absences. In response, she drafted a proposal to create small businesses that would employ local women to manufacture and sell pads made from environmentally friendly and inexpensive banana fibers. This solution has several positive results: cheaper sanitary products for the local women and girls, increased school attendance for female students and

a profitable business for the local economy, employing people from the community and utilizing local waste material from banana plantations. Her business plan incorporates a reasonable profit that can pay administrative staff salaries and create a self-sustaining enterprise that fulfills a number of unmet needs in the community. Sharpf's eventual social return on investment goes far beyond her initial concern of having a winning soccer team. Using local resources, her ideas have led to utilization of environmentally green manufacturing, created local jobs and improved access to education for girls.

Examples of social entrepreneurs have been found throughout history as catalysts of systemic change in areas such as farming and medicine. The message imparted to health advocacy professionals at the June 19th presentation is that revolutionary creativity with resources, both financial and technological, drives social innovation. In today's unsteady economic environment, solid leadership skills supported only by philanthropy may not be enough. A sustainable income source can be built into social ventures to create self-supporting initiatives.

Cipora Moskowitz is a graduate student in the Health Advocacy Program.

Faculty News

Using Patient Voice to Construct an Emergency Medicine Clerkship

Constance Peterson, who teaches *Models of Advocacy: Theory and Practice*, created an emergency medicine clerkship program at NewYork-Presbyterian Hospital. She will be making a presentation about the program in September at the European Society of Emergency Medicine Congress in Valencia, Spain. The following is an abstract of her presentation.

While the past few decades have brought significant advances in emergency medicine, these advances have occurred within a health care system comprised of complex bureaucracies which are often organized more for the benefit of service providers than consumers. Economic incentives and legal considerations have assumed tremendous importance in the delivery of emergency medicine, sometimes eroding an emphasis on patient-centered care. Emergency medicine educators are in a unique position to question whether these trends best serve patient interests and to move the system to a more patient-centered focus where the delivery of quality emergency care is dependent on attention to patient voice and issues of empowerment, autonomy, access and education are integral to the care itself. An emergency medicine curriculum designed to

meet these challenges must also accentuate the dynamic interaction between patient and provider as well as acknowledge the tension between academic study and the actual practice of emergency medicine.

Central to this clerkship curriculum model is the concept that the learning experience should be distinguished by its attentiveness to patient voice. The clerkship is designed to challenge medical students to integrate the varied aspects of emergency care delivery and to explore and analyze the dynamics of illness from multiple perspectives. The student's active participation in multi-disciplinary, collaborative partnerships with patients and health care professionals serves to realistically illustrate the complex range of skills required to identify and overcome barriers and to create micro-systems of patient care that function with integrated attention to the macro-systems in which they operate. Additionally, students are challenged to find their own voice as future emergency medicine physicians and to acquire essential knowledge about themselves by engaging in self-reflection and becoming comfortable with ambiguity and uncertainty.

Applying ethnographic research techniques, students focus on areas of communi-

cation, patient rights, the culture of the workplace, power dynamics and cultural sensitivity. Case-based problem-solving tutorials introduce students to the ethical and legal dilemmas which patients and providers encounter in the emergency setting. In didactic sessions, students expand the scope and diversity of their knowledge by exploring the historical evolution and the broad social and cultural forces which shape patterns of health, medicine, disease and illness. They examine the social implications of power inequities, new technology and scientific research. Students also acquire a comprehensive understanding of legislative and regulatory systems relevant to emergency medicine, and learn how such systems affect the health care of individuals and drive institutional change.

Subjective evaluation of this clerkship has shown that it effectively facilitates learning and professional growth in a way which ensures a theory-practice dynamic and affords students the opportunity to acquire essential patient-centered skills such as empathic communication, negotiation, conflict resolution and collaborative problem-solving.

On the Frontline in the "War of Worlds" Over Health Care Reform

Continued from page 4

than two decades of research from Dartmouth that has shown that fully one-third of our health care dollars are squandered on unnecessary tests, ineffective or unproven procedures, and overpriced drugs and devices no better than the less costly ones they replace. Hospitals and physicians compete against each other rather than collaborate and, according to Mahar, "drug-makers, device makers, and insurers decide which products to develop based not on what patients need, but on what their marketers tell them will sell — and produce the highest profits."

Informed by this view of the "medical-industrial complex" that is the root of many of our current problems, HealthBeat advocates for fundamental changes that will help

cut some of the waste, greed and subpar care out of the system. We write regularly about such key concepts as comparative effectiveness studies that will help identify the best treatments, increasing reimbursement for primary care doctors, promoting collaboration between physicians and hospitals and, finally, creating a public plan that can act as a showcase for these new measures and offer affordable, quality care to many more Americans.

Health advocacy takes many forms and can be practiced at many levels, from the individual patient to large segments of the population. But when it comes to helping to facilitate the fundamental changes necessary for health care reform, my personal form of advocacy is the written word. At *Business Week*, where I worked for eight years as Science Editor, some of the articles

we published about new developments in biotech and medical research influenced companys' stock prices. In writing for HealthBeat, I feel like our words can have a similar influence on the success or failure of health care reform.

To access the blog HealthBeat, go to www.healthbeatblog.org. For more information about The Century Foundation, go to www.tcf.org

Naomi Freundlich is a graduate student in the Health Advocacy Program.

On My Way...

Continued from page 8

I plan to make a presentation about this program at the National Neonatal Nurses Conference in Phoenix in September.

As a past LEND Fellow, I am part of a national network that provides opportunities to participate in webinars, future conferences and fellowships funded by the Maternal and Child Health Bureau. We

have access to multiple databases compiled specifically by LEND Programs and AUCDs under the MCHB. I also have access and have contributed to a Wiki on Moodle, which is an e-learning site for grantees of the HRSA/MCHB Training Program with valuable resources for families and professionals.

I experienced great personal and professional growth as a result of my participation

and remain dedicated to improving the lives of children and families. I am thankful for my LEND experience, made possible by the wonderful Dr. Karen Edwards.

Celia Bertuzzi is a graduate student in the Health Advocacy Program.

Faculty Profile: Christobal J. Jacques



Christobal J. Jacques

Christobal J. Jacques, LMSW, is an HIV Prevention Specialist with the New York City Department of Health and Mental Hygiene, Bureau of HIV AIDS Prevention and Control. He manages and coordinates activities to prevent and control the epidemic of HIV/AIDS in Brooklyn, with a special emphasis on areas with persistent health disparities.

He joined the staff of the New York City Department of Health and Mental Hygiene in 1986 and has held a variety of supervisory, management and leadership positions, including coordination of outreach and prevention education to injection drug users, oversight of the HIV Anonymous Counseling and Testing Program, Director of Community Relations for the Bureau of HIV/AIDS and Governmental Co-Chair of the NYC Prevention Planning Group. Prior to accepting his present position, he was Special Assistant to the Assistant Commissioner for the Bureau of HIV/AIDS. In that capacity, he had broad responsibilities for special initiatives and community relations.

Mr. Jacques received his Masters in Social Work from the Hunter College School of Social Work, where he majored in community organization and minored in group work. He is a graduate of the University of North Carolina School of Public Health and Kenan-Flagler Business School, where he received an Emerging Leaders in Public Health Fellowship.

His involvement with HIV prevention has been the stimulus for an ongoing examination of his professional and personal vision and his role in the various communities with whom he works. That self-reflection has helped him develop as a professional and leader by improving his knowledge base, sharpening his skills and refining his vision. Mr. Jacques will be teaching Program Design and Evaluation in the Health Advocacy Program.

Faculty Profile: Jennifer Buckley



Jennifer Buckley

Jennifer Buckley advocated for eleven years as a hospital patient representative at several large teaching hospitals, including Westchester Medical Center and Memorial Sloan-Kettering Cancer Center. Her role was to personalize and humanize the hospital experience by serving as a liaison among patients, their families and staff, and to craft resolutions to problems and recommend corrective actions to make hospital services more responsive to patients' needs. She was a member of Memorial Sloan-Kettering Cancer Center's Patient Education and Ethics Committees. She is a founding board member and continues to serve on the board of The Pink Foundation, a Westchester-based organization dedicated to providing social programming and emotional support for young women with breast cancer.

Jennifer received a BA in political science from Boston College and a MA in Health Advocacy from Sarah Lawrence in 1996. She is now the fieldwork coordinator for the Health Advocacy Program.