HEALTH ADVOCACY BULLETIN
The Journal of the Health Advocacy Program at Sarah Lawrence College
VOLUME 11, NUMBER 1 SPRING 2003

Treading Firmly Through the Medical Minefields:

How a Personal Odyssey Led to a Lifework of Advocacy

By Maggie Hoffman

I never realized that I was practicing for a lifetime of caregiving and advocacy when my father was diagnosed with acute myelogenous leukemia. After exhausting standard treatments, my Mom and I began looking into other options. I found myself selling my Dad to researchers: "I have a 53-year-old male who is extremely motivated, with great insurance and the ability to travel cross country." I had to learn medical terms and scientific concepts in order to gain opportunities in research protocols. My Dad received an autologous bone marrow transplant in Seattle and, months later, he was using an experimental, tiny, constant-infusion pump to receive small doses of chemotherapy 24 hours a day.

In truth, advocacy skills were far more necessary on a day-to-day basis, as no one is taught how to be a patient, a consumer and a self-advocate before entering the healthcare system. Family caregivers have to become advocates by proxy. In my case, that translated into: decorating the hospital room with posters from home so that my Dad would be more comfortable, checking the medications before he took them, asking a doctor to wait until he was awake before telling us the next plan of action. It was so important to keep my Dad in the decision-making loop, even when he was feeling weak and ill, even after he had a stroke and was 'not himself.'

Quality-of-life improvements were as important as the issues surrounding treatment. My parents needed support to talk to the doctors about lifestyle adaptations (acquiring a scooter, mini-vacations, etc.). Once my Dad died, at home and on his terms, I figured that I wouldn't have to interact with the medical system until taking a tour of a labor and delivery suite.

I was trying to reach that goal, but finding it frustratingly out of my reach. I had tried clomid (a fertility drug) and artificial insemination, but month after month I was disappointingly not pregnant. It is an amazing time in a woman's life—wanting desperately to have a child, marching through the fertility maze, feeling that reproduction should be an inalienable right. In vitro fertilization (IVF) required a great deal of research in order to understand just how many women became pregnant and, nine months later, brought home a healthy baby. Clearly, the first steps of advocacy are learning to ask questions and becoming educated. I must have chosen well, as my second IVF cycle was successful; I was carrying twins.

Motherhood

For the first few months, I was the most radiant, glowing, deliriously happy pregnant person. But, when I was six months pregnant, I called the high-risk obstetrician as soon as I started to feel strange: unusually crampy, scared by tiny leaks of fluid, feeling like I was getting a virus or something. The doctor insisted that, with twins, I must just be a trifle incontinent. No, I wasn't. Defiantly, I stated that I was going to have these babies, soon. He, offended at my attempts at self-knowledge, stridently asserted that, as a first-time "mommy," I was misdiagnosing the problem. Urine. Definitely urine.

Two mornings later, I felt trickles of liquid and rushed to the clinic. A different doctor's evaluation was the same: "anxious mommy." This felt like a not-so-modern take on the "don't worry your pretty little head about this" kind of thinking. That night, I had a river

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Health Advocacy Students in the Field

The Health Advocacy Program maintains a database of over 250 field placement sites. Our students, however, typically open doors to new internships in health advocacy. Even hospital placements are often outside the traditional patient representative department. At Mount Sinai Hospital in Toronto, for example, Farrah Schwartz, a Canadian student, did an internship with the Director of Human Rights and Diversity. Omega Bugembe worked under the supervision of Constance Peterson at NYP/Weill Cornell Medical Center in the Emergency Department. Also at Weill Cornell, Mel Finkelstein interned with gerontologist Eugenia Siegler in the Center for Aging. And Marlene Krammer combined patient advocacy and bioethics consultation at Brooklyn Hospital. Phyllis L'Estrange, an RN, learned about palliative care and pain management in the Hudson Valley VA system. Our Porrath Fellow for 2002, Casey Warren McDonald, interned in the Zalmen A. Arlin Cancer Institute at Westchester Medical Center. Liz Masek worked with Associate Hospital Administrator Janice Levy (HA '87) at Memorial Sloan Kettering Cancer Center.

The non-hospital internships this year were even more varied. Two students went to different Planned Parenthood offices, combining patient services and policy advocacy. Chris Fulton pursued anti-smoking legislative advocacy at the American Cancer Society. A number of students did internships involving programs for older adults. Mel Finkelstein and then Mary Tierney worked at the Jewish Home and Hospital (NYC) on a demonstration Medicare project to help older adults age at home. In a similar program in Seattle, Jody Harris interned with the PACE Program at Providence ElderPlace. At the Westchester Department of Senior Programs and Services, Ethlouise Banks developed a County-wide program—launched at a press conference held by the County Executive—to enable seniors to keep essential medical information attached to their front door in case of medical emergency. Two of our students are working with end-of-life coalitions, Jane Cordova, with the Long Island/Queens Coalition, and, beginning in September, Phyllis L'Estrange with the Westchester Coalition.

Among the new internships, Pat Stanley was a teaching assistant in an economics course—with a focus on health economics—taught at Bedford Hills Correctional Facility as part of Sarah Lawrence College's participation in the prison's college program consortium. Julie Buyon pursued her interest in new screening technologies by researching lung scans for the Center for Medical Consumers and publishing an article in *HealthFacts,* March 2003 (medicalconsumers.org), "Should Smokers And Former Smokers Have A Lung Scan?" Cindy Kemp, with the help of Pat Banta (HA '99), did an evaluation study of lupus outreach and education programs for the SLE Lupus Foundation. Desiree Perez-McDougall completed her Health Advocacy degree with a placement at the National Council for Research on Women.

In areas considered somewhat outside mainstream health or medical care, Alice Schluger worked with a pet "therapy" program at the Animal Medical Center, Deirdre Macho with a naturopathic doctor, and Farrah Schwartz with the Center for Science in the Public Interest, a nutrition advocacy organization. Jaime Lobb interned in Hope House (Independence, MO), a residential program for abused women and their children, and at Sarah Lawrence with the ACCESS program, a college sexual abuse education and awareness program. And finally, in community health advocacy, and important to all health advocacy work, Ruth Rugoff worked with Rachel Grob, Marsha Hurst and the planning group on the Health Literacy conference held in Yonkers in January. These placements are a window into the very varied world of health advocacy and a learning experience for master's students and for the Program itself. ■

From the (New) Editor:

It's wonderful to be back in the HAP environment, a blend of intellect and empathy, idealism and practicality, contemplation and activism. I hope that the *Bulletin* will reflect all of these and, in doing so, continue to be informative, inspirational, and provocative. Deb Hornstra and the previous editors have laid a solid foundation.

As Marsha Hurst writes in her column, these are challenging times for health care advocates. But there are shining success stories, some of them described in this issue, and many opportunities just waiting to be developed. Readers are encouraged to share their ideas, respond to what our authors have written, and, of course, feel empowered enough to make a difference. After all, that's what advocacy is all about.

—Lucy Schmolka

http://slc.edu/~health

The HEALTH ADVOCACY BULLETIN is a publication of the Health Advocacy Program at Sarah Lawrence College, One Mead Way, Bronxville, New York 10708.

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Medicare Prescription Drug Coverage: Going, Going...Where?

By Melville G. Finkelstein

This article, by a 2003 Health Advocacy Program graduate, was originally written for his "Health Law" class last fall. It has been updated to provide the most current information available at press time. A related advocacy piece appears on page 11. Readers are invited to respond to both with their insights and opinions by email: health@slc.edu.

For more than 40 years, the federal government has been trying to control the pharmaceutical industry in the United States. During this time, drug expenditures have been the fastest growing component of health care costs. American consumers pay more for drugs than consumers in any other country, the hardest hit segment of the population being the uninsured elderly. Today, there is a public outcry for government to contain prescription drug prices and to offer a prescription drug benefit plan to Medicare beneficiaries. In the past, attempts to add such a benefit have been unsuccessful. Intense lobbying from the pharmaceutical industry and the political parties' concerns about how government would pay for the coverage are among the many obstacles that have hindered efforts to do so. With the baby boomers "coming of age," however, there will be increased pressure on government to keep them healthy, a pressure which will require that something be done for current and future Medicare enrollees. In considering this question, it is useful to review some historical background of the pharmaceutical industry, examine the current state of the prescription drug issue, as well as look to the future. The time has come to determine the best and most cost-effective way to provide prescription drug coverage to Medicare beneficiaries.

Some Historical Background: the drug bill of 1962

Until the 1950s, the drug industry basically had free rein in the United States. There were few regulations concerning pricing, advertising, naming, labeling and licensing of prescription drugs. Then, early in that decade, a few politicians became interested in examining pharmaceutical companies, their pricing policies and monopolistic behavior.

The story, it might be said, began on a cold morning in February 1951, when Walton Hamilton, an attorney in Virginia, woke up ill, saw his physician, and received a prescription for one of the new antibiotic wonder drugs, chloromycetin. When Mr. Hamilton went to purchase this drug he could not believe its high cost. Indeed, after expressing concern to his doctor, he discovered that the alternatives were just as expensive.

Walton Hamilton, who had been a professor of law at Yale and a consultant to the Anti-Trust Division of the Department of Justice, discussed the matter with his wife, Dr. Irene Till, a PhD who worked part time as an industrial economist for the Federal Trade Commission (FTC). Dr. Till approached her immediate supervisor, Dr. John M. Blair, chief of the FTC's Division of Economic Reports, and together they recommended that the FTC undertake a preliminary study of the antibiotic drug market. Although nothing came of that study, it was the beginning of a decade-long investigation into the pharmaceutical industry that eventually led to an effective drug bill.

Also interested in this issue was Senator Warren G. Magnuson, Democrat from Washington and member of the Labor, Health, Education and Welfare Subcommittee of the Senate Appropriations Committee. In 1953, he began to focus on two related concerns: the major expense that drugs represented in federal and state welfare programs and complaints about drug prices from elderly constituents. Upon study, Senator Magnuson found that retirees spent as much as a third of their income for medication. He also noticed when he was traveling in Sweden that some American-made drugs cost only 20% of what they cost in America and wondered why that should be the case. Senator Magnuson speculated that an investigation into the drug industry might show markups of "four hundred and five hundred per cent of the cost of production" (Harris 1964, 6). He urged the FTC, under Chairman Edward F. Howrey, to undertake such an investigation. When Senator Magnuson became the head of the Senate Independent Offices Appropriations Subcommittee in 1955, he was still awaiting completion of the FTC study. Finally, in 1958, a year after John W. Gwynne had assumed the Commission chairmanship, a superficial report was issued, neither as comprehensive nor complete as Magnuson had hoped.

Meanwhile, in January 1957, Senator Estes Kefauver, Democrat from Tennessee, became the new chairman of the Senate Subcommittee on Antitrust and Monopoly, which investigated industries and their pricing practices. Kefauver named Dr. Blair of the FTC as his chief economist and Dr. Till as his associate. In 1958, a serious investigation of the drug industry finally began. That decision was triggered when Dr. Blair, looking at a quarterly report from the FTC, determined that drug industry profit margins were considerably higher than those of any other industry. With this new information, Dr. Till, who had continued to press for an investigation of the pharmaceuticals, was named to head the study.

The Till study revealed price fixing and collusive dealings among companies manufacturing the same type of drugs. Drug prices were dictated not by market competition but by the drug producers who constrained supply to inflate prices (Harris 1964, 20-25). These findings led Senator Kefauver to conduct Senate Subcommittee hearings on the drug industry in 1959, a move that was greeted with tremendous support from patients, physicians and the public in general. The hearings provided further evidence that enormous profits were being made on pharmaceutical sales, that manufacturers were untruthful about medication side effects, and that other government agencies, such as the Food and Drug Administration (FDA), were being co-opted by the very companies they were supposed to be regulating.

The Kefauver hearings ultimately resulted in the passage of a drug bill in 1962 that lowered drug prices, increased competition and provided more information to the buyer. Twelve long years

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between my legs. I gathered my nightgown, bed sheets and the towels I used to mop up the flood and sat, cursing, next to my then-husband as we drove to the hospital.

We banged through the labor and delivery doors and the exam revealed one twin's sac had lost all of its amniotic fluid. I was admitted to a bed and told that I could relax. Instead, I gave birth to Molly and Jacob, three months prematurely.

Such a harsh lesson: no matter how clearly you state a problem, if no one is listening, you can't communicate. Effective advocacy may mean finding a different set of ears. In retrospect, possibly a nurse manager or a hospital administrator might have been more open to hearing from me.

The twins had an exceedingly tough time in the neonatal intensive care unit (NICU). Within the first few hours after birth, I had to give permission, the first of many, for the insertion of a chest tube to help Jacob's collapsed lung re-expand. The kids were on ventilators, feeding tubes and numerous IV medications. I learned how to partner with the NICU nurses and how to ask questions of the doctors in order to get the answers I needed. When Molly was found to be blind (retinopathy of prematurity), I found surgeons in both Boston and Memphis and convinced the hospital to transport Molly for assessments.

After four and a half months, the twins came home. We were given a CPR class, and then sent out the door! Without a realistic discharge plan, my learning curve was steep. I became submerged in the minutiae of early intervention therapies, providers, agencies and funding streams. Molly and Jacob's local pediatricians had to be updated on their therapeutic needs; the special education teachers and therapists, sent to initiate Early Intervention (E.I.), had to be educated about the twins' medical conditions. An advocate has to be the ultimate repository of all salient information. Knowledge might not be power, but it is a confidence-booster.

The New Survivors

Isolation was beginning to kill me, though. Most mothers had opportunities for fellowship—through Mommy 'n' Me, or play groups or even chance meetings at the park. Mothers of children with special healthcare needs are either stuck at home or in the hospital or, if out, stared at by well-meaning people. I yearned for a body of peers and decided to start a support group. I heard about Sandy, a social worker who had a grant from the Office of Mental Retardation and Developmental Disabilities. She came to my home every Thursday night, ate my chocolate cake and reassured me that folks would soon learn of our weekly meetings.

It took a few months to get established, but Molly and I were 'frequent flyers' on the inpatient floor, so I advertised the group to other mothers, nurses, doctors and the itinerant E.I. Providers. Soon parents from Nassau, Suffolk and Queens found their way to my living room each Thursday. Very quickly, the members and I realized that, although Sandy was (and is) the loveliest, most compassionate person, her professional standing was getting in the way of our developing a peer connection. Sandy stopped attending the meetings. We parents received so much strength from each other and shared the emotional toll. We swapped parenting tips (how to unclog a feeding tube, how to add lateral supports to a car seat, how to interview a neurologist, how to block an in-law's cutting remarks).

Our group, the New Survivors, developed into more than just a weekly support and networking meeting. We began to advocate for our children and families *as a group*. We testified before the Commissioner of the Office of Developmental Disabilities about the need for more funding. We wrote to state legislators to agitate for increases in the "slots" for Medicaid waivers. We faxed Congresspersons to alert them to our home nursing shortages. We signed on to a national Life Span Respite bill. One voice is easy to tune out. A chorus of voices is much harder to ignore. As a group, we had to understand that no one is lining up to 'make a place at the table' for families caring for a chronically ill or disabled child. If we don't make our own case, we vanish behind the wheelchairs we push and the hospital beds we sit next to.

My turn came soon enough. Our family's comprehensive health insurance policy was cancelled—the company went out of business. Molly's intravenous medications cost close to $2000 per week. New York State had a Medicaid waiver program called Care-at-Home. It granted Medicaid to a severely ill child, even if her family lived above the poverty income eligibility. My county was choosing not to participate. I called my state senator and assemblyperson. I contacted the Governor's office. I was not heard.

I phoned a columnist at *Newsday,* our local newspaper. After checking the information I gave him, he published an emotion-charged column about our situation. *The very next day,* County Medicaid officials offered to help *if I would keep it our secret*. I couldn't stand the thought of another family living the same torment as we had. So the County taunted me: we now have a program; too bad we don't have a qualified evaluator to assess each family and we are unable to initiate the program. On my own, I was able to recruit a credentialed evaluator, the program began accepting children, and I began educating every family I knew about the entitlement.

My family life was falling apart. My then-husband was emotionally failing, strained by having two children with disabilities. While I was overjoyed at having just given birth to a healthy baby girl, he only felt that she added to the chaos, crying all the time. I became a single mother when baby Rosie was ten weeks old; the twins were two and a half.

Quality of Life

The most difficult advocacy I ever had to deal with was Molly's end-of- life care. Molly was never going to be well enough, nor developmentally advanced enough, to lead a 'productive' life. In many ways, I found that a relief. Her teachers and I could focus on quality-of-life activities. Molly learned to switch on her music tape, and she made sure that we knew when she wanted attention. Because Molly did not have a progressive, degenerative disease, I never really thought about limits on her longevity.

When she was three and a half, after a particularly acute pediatric ICU hospitalization, Molly began to have frequent bouts of pneumonia. The frequency increased within the year, and her "senior" pediatrician called me into his office for a meeting. He explained that Molly could not continue to live on intravenous feedings indefinitely, as they would make her susceptible to systemic

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blood infections. Additionally, her lungs were not as flexible as they once were, and Molly's seizure condition seemed worse. The doctor wanted to help me begin to address how aggressively we would treat Molly's subsequent illnesses. He wanted me to know that, if Molly needed breathing assistance with a ventilator, she would not be able to be weaned off.

I want to emphasize how remarkable this interchange was. So few physicians are willing to make the time and to attempt a discussion that, while clearly distressing, desperately needs to be explored. We talked about quality of life and that I would not place Molly on a vent. I could not, however, talk about an autopsy. I was told that Molly would live another six to nine months.

Fifteen months later, it happened. I went to the bathroom and, at the same time, Molly's RN went to the kitchen for a glass of water. When I came out, Molly was purple, seizing and having difficulty breathing. I called the doctor and he reminded me of my resolve to enforce a Do-Not-Resuscitate order (DNR). In reality, it was a Do-Not-Intubate order (DNI), but many healthcare providers use DNR to cover both terms. When I ran Molly into the Emergency Department, I saw a resident come at her with an ambu bag (to manually breathe for her until she could be intubated). I stated that she was "a DNR" and the resident led us to a bed. Another of Molly's doctors met us there and ordered oxygen, medicines and breathing treatments. None of them worked. By then, the "senior" doc had arrived, and he told me that I could change my mind and put her on a vent. No. I asked if I would have to take her home, and he told me that she could go into an ICU 'step down' unit (to die.)

It was there that active advocacy came into play. ICU physicians, almost by definition, employ aggressive medicine. The chief of the Pediatric Intensive Care Unit (PICU) wanted to place her on a ventilator and I had to restate my wish for a DNR. The emotional toll of requesting a Do-Not-Intubate order over and over for one's child is obscene. The PICU chief even called me a sadist. Eventually, Molly's other doctors arrived in time to corral the chief into a huddle, where they explained Molly's history. They had to vouch for me, validating my "credentials" as a caring, invested mother. Molly died within two days.

Creating Project DOCC

Two of my New Survivor friends, Donna and Nancy, and I became involved in our hospital's Parent Advocacy group. Eventually, we received permission to lecture at Professorial Rounds. This weekly academic session was specifically for pediatric residents—physicians-in-training. We talked about "chronicity," school-health concerns and the special pleasure achieved when we found physicians to truly partner with us in the care of our children. Although grateful for the opportunity to talk to tomorrow's doctors, we wanted more. At one of the Advocacy meetings, Donna talked about her dream, a standardized chronic care curriculum, and the staff person said, "Go write it."

We did. The three of us spent three months in Donna's basement, creating Project DOCC—Delivery of Chronic Care. We defined the tenets we wanted every pediatric resident to learn. Every family with a child with special healthcare needs has to have three essential ingredients in order to live in the community successfully: (1) a pivotal physician, (2) referrals to community resources and parent-to-parent support and (3) a focus on quality of life.

Project DOCC has developed three components in order to illustrate our lives and our needs: a Home Visit, a Parent Interview and a Grand Rounds Panel Presentation. Parents are the teachers and the coordinators of the programs. The three of us developed a two-day training program to assure that our Family Faculty members become effective teachers. To date, we have trained 24 Project DOCC teams coast-to-coast and one in Australia.

We expanded our programming to include a four-component Older Adult curriculum. Additional plans include Project DOCC—Genetics; Project DOCC—End-of-Life Care; Project DOCC—School Health; and Project DOCC—Transition to Adulthood. Nothing feels as powerful as participating in the education of future doctors. It is exhilarating to use one's own experiences to document the needs of a large and ever-growing chronic population.

Today

Jacob is now fifteen. He has mild cerebral palsy, tremors and pervasive developmental disorder (considered an autism 'spectrum' disorder). He goes to a special, segregated school. He uses orthotics to help him walk. Jacob receives

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Resources: Chronic Illnesses and Disabilities

Project DOCC—Delivery of Chronic Care. 1-877-773-8747 (toll free). ProjDOCC@aol.com

New Survivors—peer support for parents of children with special healthcare needs. ProjDOCC@aol.com

Long Island Network for Parents of Children with Special Healthcare Needs. BobPolly@aol.com

Resources for Children with Special Needs (info and referral for NYC). 1-212-677-4650

Genetic Alliance (information and advocacy for genetic conditions). www.geneticalliance.org

Family Voices (Advocacy for families of children with special needs). www.familyvoices.org

ElderPage: Information for Older Adults and Families. www.aoa.dhhs.gov/elderpage.html

National Library of Medicine's MEDLINE (national medical database). www.nlm.nih.gov/databases/freemedl.html

Children's Hospice International. www.chionline.org

Hospice Foundation of America. www.hospicefoundation.org

For information and referrals regarding suspected health and disability issues, contact your local Early Childhood Direction Center (throughout NY State). For networking between parents, call Parent-to-Parent (across the US).

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after Walton Hamilton took his concern about prescription drug prices to his doctor, legislation regulating the drug industry was signed into law by President Kennedy. This legislation could not, however, address a range of other issues with regard to prescription drugs. For instance, it did not anticipate Medicare coverage.

Enter Medicare

Medicare coverage began on January 1, 1966, and, from its inception, coverage of prescription drugs has been an issue. The original 1965 Medicare proposal included prescription drug coverage, but this provision was eliminated because of "unpredictable and potentially high costs" (Barry 2002, 4). A few years later, the Nixon administration considered adding a prescription drug benefit to Medicare, but opted against it because of growing health care cost inflation. The third attempt was in 1988 with passage of the Catastrophic Care Act, which protected Medicare beneficiaries from catastrophic out-of-pocket costs and also provided prescription drug coverage. That law was repealed approximately one year later after the drug industry, seeing its profits threatened, put pressure on politicians to eliminate it. Another reason for repeal was that higher income beneficiaries, who already had supplemental private coverage, did not want to subsidize a drug benefit for beneficiaries through an increase in Medicare premiums. The Clinton administration also had a proposal to expand Medicare benefits to include drug coverage, but the measure died in 1994, never reaching the House or Senate for debate.

Today, lawmakers have another opportunity to address the issue of prescription drug coverage in Medicare. Both parties concede the importance of passing a drug benefit program, but are divided on two issues: how much to spend and how to deliver it. A key question is whether the program should be run through private health plans, as the Republicans want, or directly by Medicare, as the Democrats prefer. At the same time, the pharmaceutical industry is prepared to oppose any government proposal which tries to control the costs of the program through drug price regulation. It seems likely that some kind of benefit plan will be enacted, but it will take cooperation and reconciliation between the ideologies of the political parties and acceptance by the drug companies, physicians and Medicare beneficiaries before it becomes a reality.

The Pressure Mounts

The Kefauver investigation in the late 1950s and early 1960s revealed that drug companies were making enormous profits. A 1958 FTC report comparing manufacturing companies showed that drug industry profits of 18.9% of invested capital and 10.8% of sales after taxes were twice the average of the other manufacturing industries included in the report (Harris 1964, 17). Forty years later, in 1999, *Fortune* magazine reported that the pharmaceutical industry realized an average 18.6% return on revenues and was still the most profitable industry in the United States (Angell 2000, 1902). Furthermore, Americans still pay more than either Europeans or Canadians for the same drug, another factor that has not changed in the last four decades.

As expenditures for drugs in the United States continue to rise, the drug industry has once again been placed under a microscope. Expenditures for prescription drugs are the fastest growing component of health care costs, increasing at a rate of 15% a year (Angell 2000, 1902). The increase is attributable both to greater use and to higher prices. The pharmaceutical industry justifies the increase in prices, claiming "that someone needs to pay prices high enough to attract the investment necessary to sustain the industry's extraordinary research and development costs" (Angell 2000, 1902). While the industry agrees that prescription drug coverage is desirable, it maintains that this should not be achieved through price controls or government interference. Pharmaceutical spokespersons insist, as they have historically, that such controls would stifle innovation. They point to all the effective drugs that have been produced in the last 20 years when there has not been interference.

To sustain its position with lawmakers, the industry, through its organization called Pharmaceutical Research and Manufacturers of America (PhRMA), supports a very active lobby. Over the last 10 years, PhRMA and its member drug companies have spent more than $1 billion to influence the legislative process (Edsall 2002, A08). But the pharmaceuticals have been facing opposition. Besides senior citizens wanting to control the prices of prescription drugs, companies such as General Motors, Wal-Mart Stores and Motorola have formed an alliance, Business for Affordable Medicine (BAM), to reduce employers' prescription drug costs. BAM played an important role in persuading the Senate to pass generic drug legislation.

Today, 40 million elderly and disabled persons are enrolled in the Medicare program, which generally does not pay for their prescription drugs. Most beneficiaries, however, use prescription drugs on a regular basis, and as of 1998, 73% had some form of private prescription drug coverage. The balance, more than nine million people, went without (Iglehart 2001, 1010). Beneficiaries without coverage pay the highest prices for prescription drugs when they are purchased at community pharmacies.

Medicare currently does provide drug coverage to beneficiaries who are inpatients in hospitals or skilled nursing facilities. It also pays for some prescriptions used by outpatients, such as immunosuppressive agents, drugs for patients with renal disease, and palliative medications for hospice enrollees. Recently the Bush administration has taken a new approach to controlling Medicare's prescription drug costs, applying a cost/benefit analysis when making coverage decisions. Medicare currently covers about 400 medications, but officials have begun to compare new, more expensive drugs to older, lower-priced ones to determine if the therapeutic difference justifies the additional expense. The drug industry is in an uproar over this trend, claiming that "the government . . . lacks the legal authority, the expertise and the clinical data to make such decisions" (Pear 2003).

Congress has been supporting the idea of a Medicare drug benefit, but members have been unable to agree on how to pay for it or how it should be run. Increasing costs have been the catalyst driving Congressional interest. In 1999, total health care spending reached $1.2 trillion, an increase of 5.6% over the previous year. At the same time, expenditures for prescription drugs increased by $100 billion, an increase of 16.9% (Iglehart 2001, 1010).

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Sarah Lawrence Hosts Seminar for Journalists

End-of-life issues, gene therapy, the Human Genome Project, stem cell research, cloning and ethical concerns surrounding these and other topics were addressed by Sarah Lawrence College faculty in a seminar constructed for journalists entitled "Genetics, Ethics and Health Advocacy." The three-day course, held April 9-11, was one of 20 CASE Media Fellowship programs offered in 2002-2003 by colleges and universities around the country.

According to CASE (Council for the Advancement and Support of Education), a Washington-based organization, the annual program offers journalists "an opportunity to interact with renowned scholars, explore the intricacies of important issues and discover the latest ideas at leading institutions around the world." The Sarah Lawrence seminar, taught by faculty in the Health Advocacy and Human Genetics graduate programs and the undergraduate Science and Science, Technology and Society programs, focused on the intersection of human genetics, ethical issues and advocacy. Participants ranged from writers and reporters to a research librarian.

The sessions on Health Advocacy provided an introduction to the emerging field and visits to classes that illustrated elements of professional training. One class, "Illness Narratives: Understanding the Experience of Illness," gave program participants a glimpse of the benefits of writing about illness for both patients and health care providers. "Models of Advocacy: Theory and Practice" focused on advocacy and end-of-life issues, including palliative and hospice care.

Sessions on Human Genetics offered an overview of major scientific issues, including the controversial topics of cloning, stem cell research, the Human Genome Project and its implications, identification of genes for particular traits (disease and behavioral) and transplantations. The journalists visited a class on "Genetics, Biotechnology and Society," where the day's focus was on gene therapy and pharmaceutical research, and concluded with a discussion of the role of the genetic counselor in helping patients to make potentially life-altering decisions.

The program's final day was devoted to in-depth discussions of ethical issues. These included informed consent; competency/capacity to make decisions; refusal of treatment; withholding and withdrawal of life-sustaining treatment; physician-assisted suicide and euthanasia; confidentiality; maternal-fetal conflicts and treatment; physician-patient relationships, managed-care and professional obligations. Alice Herb, who teaches bioethics in the health graduate programs, presented the issues and led the discussion.

"It was excellent," said Sambhavi Cheemalapati of Consumers Union, "not like other conferences where participants hear a PowerPoint presentation, receive informational packets and go home. We were all creating the experience, questioning along with the students, and were very engaged—the best way to be educated. The classes were extremely interesting; then we had lunch with the faculty, where we could talk at the 'applied' level. I really enjoyed it."

Future seminars will be planned.

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Besides an increase in pharmaceutical use because of population longevity and expanding treatment options, expenditures have grown because of coverage provided by third-party payers, health plans with low co-payments, and direct marketing programs aimed at consumers. According to a senior government economist, Medicare beneficiaries are expected to spend $1.8 trillion on prescription drugs over the next decade (Reuters, 2003). Many have been joining health maintenance organizations (HMOs) because of the drug coverage they provide. Until recently about 15% of all Medicare beneficiaries had drug coverage through an HMO. Many HMOs are dropping out of the Medicare program, however, citing inadequate payment rates as the reason.

A Modest Beginning

Even though a prescription drug benefit has not yet been added to the Medicare program, there have been some efforts, public and private, to try to lower out-of-pocket costs to beneficiaries. In 2001, for example, the Centers for Medicare and Medicaid Services (CMS) announced a government-sponsored program utilizing Medicare Rx Cards. Under this plan, pharmacy benefit managers would apply the combined purchasing power of Medicare enrollees to negotiate discounts from manufacturers and pharmacies (Albert 2003). Before it went into effect, however, a preliminary injunction was issued in response to a lawsuit filed by the National Association of Chain Drug Stores and National Community Pharmacists Association.

CMS modified the Medicare Rx plan in hopes of persuading the court to lift its injunction. The new version, called the Medicare-Endorsed Prescription Drug Card Assistance Initiative, included some improvements: It required sponsors to provide better access to retail pharmacies, expanded opportunities for pharmacy organizations by relaxing some of the qualifying criteria, allowed card sponsors to offer two program designs, ensured that beneficiaries would have access to stable formularies and prices, and gave beneficiaries improved privacy protection. CMS claimed that it would save seniors 10-15%, up to $1.6 billion annually, would educate them about their choices and provide information on how to buy prescription drugs at lower prices. One goal was to promote the use of generics. It would have been particularly helpful to beneficiaries who do not have any drug coverage.

As described by Thomas A. Scully, CMS administrator, this plan is a "building block" toward a more comprehensive plan that will be approved by Congress at some point (Teske 2002, 2428). On January 29, 2003, however, the Federal District Court for the District of Columbia permanently enjoined CMS from continuing with the drug card initiative, ruling that CMS and the Health and Human Services Department had exceeded its authority under the Medicare Act. According to CMS administrator Scully, agency officials are considering their options and whether they will appeal the decision.

A different approach to reducing the cost of prescription drugs for all people, especially seniors, is President Bush's proposal to limit brand name-drug

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companies from delaying the sale of generics. Generic drug legislation passed the Senate in July 2002, but was not addressed by the House of Representatives during the session. Drugmakers oppose the bill, but it is widely supported by the public. In an AARP poll of adults over 45, "84% of respondents believe that making generic drugs more available is an important part of the solution to rapidly increasing drug prices" (Rovner 2002).

While the federal initiatives are debated, efforts at the state level to reduce drug prices are making some headway. In 2000, Maine enacted its Rx Program, a drug discount plan that pressures drug makers to discount prices for all uninsured residents. The pharmaceutical industry immediately challenged the plan. The case reached the U.S. Supreme Court, which, on May 19, 2003, ruled that Maine may move forward, rejecting the industry's claim that the program is unconstitutional. The case now returns to Federal District Court in Portland to determine whether the plan, in its administration, will violate the federal Medicaid statute. That issue turns mainly on factual findings regarding the program's effect on the state's consumers.

Eighteen other states, including Colorado, Florida, New Jersey, New York and Ohio, have also initiated legislation in the same vein; they feel the Supreme Court ruling will make it easier for them to proceed. Two states, Hawaii and Illinois, have already enacted similar measures. Many federal legislators insist that Medicare should follow Maine's lead and offer prescription coverage to all seniors. The Supreme Court's decision on Maine Rx has opened an avenue of further debate.

In the private sector, seven major drug companies have sponsored a program called Together Rx. Created when it became obvious that Congress would not enact a Medicare drug benefit in 2002, the program offers prescription drug discounts of up to 40% to low-income (not exceeding $28,000 for a single person, $38,000 for a couple) Medicare patients who have no other drug coverage.

The plan encountered difficulty when CMS Administrator Scully informed drug makers that they were required to offer the same low prices to Medicaid patients. This caused two drug manufacturers in the program to raise their prices for Together RX cardholders. The two companies claimed that seniors were being penalized because the government wanted the same lower prices offered to both Medicare and Medicaid patients, and that it is just too expensive to provide the same discount for both groups.

In response to the negative impact of this position, Administrator Scully reversed his decision and advised the companies that they would not have to give the same prices to Medicaid patients. As a result, the lower prices for Medicare beneficiaries were reinstated and refund checks were sent to members who paid higher amounts. In addition, the seven major drug companies are going to include generic drugs in the program, offering further discounts to low-income elderly. Eckerd drugstores, for example, began discounting generics by 30%, even though they say generic drug manufacturers are not helping with the discounts.

As of March 21, 2003, there were nearly 600,000 seniors already using the Together RX card (Pallarito 2003). Nevertheless, enrollment levels vary, ranging from a few hundred in Washington, D.C. to many thousands in Florida and Texas. Together Rx and the National Council on the Aging are working to promote public awareness, targeting those areas with low enrollment.

That a Medicare drug benefit will be offered through the Medicare program seems probable. How and when it will be accomplished has to be determined by our lawmakers.

Congress Reacts

It is clear that there will have to be a reconciliation of political ideologies if a prescription drug benefit is to be added to the Medicare program. Democrats and Republicans both understand their constituents want such a benefit. Questions arise in the way each proposes to accomplish this task. What will the coverage be? How much will enrollees have to pay? How much will it cost the government? How will it be financed? Should coverage be provided directly by Medicare or through private plans?

Last year, Democrats and Republicans in both houses proposed several plans to provide a Medicare prescription drug benefit. They are described in the table below. A Republican-backed bill, approved by the House of Representatives, would allot $320 billion over eight years for drug coverage. The legislation would allow Medicare beneficiaries to purchase prescription drug coverage from private insurance companies. Under this bill, Medicare seniors would pay a $33 monthly premium and $250 annual deductible. The legislation would exempt low-income seniors from the premium and deductible, and cover 80% of annual drug costs up to $1000. Fifty percent of costs would be covered up to $2000, with no coverage between $2000 and $3700. After $3700, a catastrophic benefit would take effect. For this bill to become law, it would have had to be approved by the Senate. However, in the Senate, at least two different bills were debated. Table 1 compares the elements involved.

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Table 1. 2002 House and Senate Proposals

Plan Element	House Republican Bill - Approved	Senate Republican Bill	Senate Democratic Bill
Premium	$33.00 per month	$24.00 per month	$25.00 per month
Deductible	$250 per year	$250 per year	No deductible
Co-pay	20% co-pay on costs from $250-$1,000; 50% co-pay on costs from $1,000-$2,000	50% co-pay on costs from $251-$3,450	$10 co-pay on generic drugs; $40 co-pay on preferred brands; $60 co-pay on non-preferred brands
Out of Pocket "Gap"	No coverage after $2,000	No coverage after $3,450	No gap
Catastrophic Coverage	After $3,700	10% after $3,700	At $4,000

New Communication Mini-Course Debuts

A new HAP mini-course, "Communicating with Patients" (1 credit, 7 sessions, no papers to write), debuted during the fall semester. Taught by Laura Long, who holds an MS from SLC's Human Genetics Program, the course focuses on communication techniques that allow advocates to discover what patients *really* need and to respond in a constructive manner.

While recognizing that advocates require proficiency in a number of different communication milieus, including public speaking and lobbying, it was decided to have this course concentrate on those skills most helpful in talking directly with patients. "Most people simply do not talk openly about their needs," says Long. "Those in painful or anxiety-provoking situations are even more indirect. This reality can leave advocates thinking they are being helpful when in fact they have misinterpreted the patient."

The two primary objectives of the new course are (1) to understand how different communication techniques work in conversation and (2) to learn how to use these techniques in order to take oneself out of the conversation and focus solely on the patient. "These are very difficult concepts to understand and skills to learn," says Long. "We are taught from an early age to get our own points across to others. Suddenly, we are in a profession that requires hearing and responding to the other person's point, responding with understanding and compassion, regardless of how that person presents it. This requires a communication selflessness that most of us have to be taught. To understand just how difficult this is, think of talking to a patient who has made a decision to refuse life-saving treatment. You have to push your feelings aside and focus completely on the patient's point of view in a way that she knows that you are completely focused on her."

Long came to the course with a keen appreciation for the effects that various communication techniques can have. For the last 15 years, she has worked with people at high risk for contracting HIV. In that capacity, she developed training programs for professionals to help them talk to patients/clients about their risk factors, sex and drugs, and how to reduce the risk.

"Unfortunately, simply saying to someone 'Use a condom' does not result in condom use," Long notes. "People do not want to change the way they have sex. Professionals do not want to talk about things that make them uncomfortable. Change in this area requires both the affected individual and the professional to let go of very deeply held beliefs and to take a leap of faith into a new paradigm of personal relationships. Both the original behaviors and the change to new ones are very emotionally based, so communicating on a rational, logical plane simply does not work. I need to understand deeply how a person feels about sex and condoms. What does the condom mean? I need to understand the anger of professionals. What are they trying to avoid?

"Communication techniques are extremely important in trying to understand another person. Even subtle changes in wording or voice tone can have dramatic effects in one's relationship with another person and/or understanding of that person's situation. A more precise understanding of the patient can change an advocate's approach 180 degrees. Using reflection, silence or questioning effectively will qualitatively change the course the patient/advocate relationship takes, leading to an outcome that more accurately reflects the patient's actual needs and desires.

"I was most impressed one time when I heard a person speak on the difference between being cured and being healed. Curing is a physical process; healing is an emotional process. Our modern health care system does a good job of curing people, but a bad job of healing them. Healing requires that health care professionals acknowledge a person's emotional place. I think that much of our dislike of our health care in this country could be alleviated if more professionals would spend time communicating *with* the patient rather than *about* the patient. I hope that those who take the course will leave with a greater ability to walk this line." ■

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The amount allocated in the Congressional budget for this benefit in 2002 was $300 billion, but both Senate bills exceeded this amount. The Democratic bill would have cost $500 billion from 2004 to 2010; the Republican bill, $370 billion from 2005 to 2012. Neither was enacted. As of late May, 2003, no new bills have been introduced, although the Republicans are speaking in terms of $350-400 billion, the Democrats $800 billion.

The White House Weighs In

The most recent Medicare prescription drug benefit proposal was put forth by President Bush in March of 2003. It offers seniors a choice of three options. The first is to stay in the traditional Medicare plan and continue receiving care as they do now without overall drug coverage. This plan would include enhancements such as the Drug Discount Card, saving seniors 10-25% off pharmacy prices. The second, called Enhanced Medicare, would offer a choice of multiple private insurers that would integrate existing Medicare services with prescription drug coverage. The third choice, Medicare Advantage, a modified version of the Medicare+Choice managed care option, would allow low-cost coverage through managed care with comprehensive drug coverage. The choice of doctors would be limited to those who participate in the HMO. According to the White House plan, low-income beneficiaries would receive a $600 annual subsidy to cover their drug bills and catastrophic out-of-pocket costs would be capped at an annual dollar amount not yet determined. An amount of $3000 to $4000 has been mentioned.

These plans vary significantly in the types of coverage they offer and their proposed costs. With the number of Medicare beneficiaries growing from 40 million today to a projected 56 million in 2017, the problem of inadequate drug coverage for the elderly will soon become a crisis. The elderly population represents only 12% of the U.S. population, but accounts for one third of the drug expenditures (Soumerai 1999, 722), and these numbers will

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continue to increase with the development of more and better medications.

The future of the Medicare prescription drug benefit, indeed, the future of Medicare itself, depends on lawmakers' reaching bi-partisan agreement about spending and coverage. Decisions must be made about whether to allocate additional federal health care funds to provide Medicare coverage of prescription drugs or other benefits. Some argue that providing health insurance to cover uninsured persons under the age of 65 might be a better use of any new federal health care dollars. For lawmakers to make drug legislation less costly, there will have to be a sharing of costs by the beneficiaries through premiums and deductibles. This might limit access by low-income beneficiaries, although provisions could also be made to deal with this problem. In addition, pharmaceutical prices might be regulated to give Medicare enrollees the same discount on drug prices that is given to federal health insurance plans. This discount currently is about 40%. Of course, with every remedy there is a problem, and including Medicare in the federal health plans receiving discounts might induce drug companies to raise prices charged to federal programs and to the private sector as well. The pharmaceutical industry is prepared to battle through legislative lobbying to avoid controls of its industry.

Congress must also consider other areas of concern, such as physicians' being influenced by drug companies to prescribe high-priced drugs instead of their generic alternatives, the over-use of the drug benefit by beneficiaries, and the impact of an increase in payroll taxes to finance a Medicare drug benefit.

And Now…

On March 7, 2002, Thomas A. Scully, Administrator for Medicare and Medicaid, testified at Senate Finance Committee hearings that Congress has been debating the need for prescription drug coverage since it repealed the Catastrophic Care Act in 1989. In actuality, prescription drug coverage has been an issue for 40 years. Today, the pharmaceutical industry is the most profitable industry in this country—at the expense of the American public, which pays the highest prices for prescription drugs in the world. And some 33% of elderly people who lack insurance coverage for prescription drugs suffer the most. Even working people with decent health insurance are demanding price relief as copayments and deductibles for drugs climb steadily. With prescription drug costs rising faster than health care costs, there must be a social obligation to ensure access to medications for elderly citizens. Those who reject this premise have to at least recognize "that the lack of access to essential medicines for the growing number of chronically ill persons is likely to result in increased hospital and nursing home costs" (Soumerai 1999, 722). It is essential that Congress reach some kind of solution as quickly as possible. Quickly, of course, is a relative term when it comes to getting legislation passed. At least some early measures have been taken, such as prescription drug discount card programs, to provide some modest interim relief for Medicare beneficiaries.

When Walton Hamilton became ill in the winter of 1951 and went to the pharmacy to purchase the antibiotic prescribed by his doctor, he could not foresee the impact his experience would have on prescription drug policy in this country. Despite the frustratingly slow pace, at least now, half a century later, the country appears to be moving toward meaningful legislation to control medication costs and increase access. A Medicare prescription drug benefit will eventually be added to the Medicare program, but it will take much more discussion and reconciliation by our policy makers. There will also have to be a sharing of responsibility by the pharmaceutical industry, the medical profession and the general population to get this accomplished. Congressional leaders have announced their intention to push legislation through the House and Senate by July 4th and to deliver a bill to the President by autumn. Medicare prescription drug coverage: Going…going…where?

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HAP Graduate Named SLC Associate Dean

A warm welcome back to Rachel Grob (HA '92), who was named SLC Associate Dean of Graduate Studies as of January, 2003. After earning her Master's Degree, Grob worked for five years at the Westchester County Health Department as legislative analyst and supervisor of children's public health programs. She then moved to the Andrus Children's Center in Yonkers, where she served as Director of Policy Analysis and Planning and Coordinator of the Yonkers Early Childhood Initiative until assuming her new post. For the past four years, she also taught a core interdisciplinary course in health advocacy in the HAP.

"Coming to Sarah Lawrence full time has been wonderful," says Grob. "In my new role, I'll have the chance to work with program directors, faculty and students on projects related both to the college's internal programming and to its external relationships. There is so much that is exciting going on in graduate studies using the Sarah Lawrence pedagogy to educate adults for scholarship and action. It's gratifying for me to be part of the processes now under way here to help the graduate programs grow and become more integrated with each other, with the undergraduate college, with the local community and with their professional fields."

No Medicare Prescription Drug Benefit from this Congress

By Deborah Hornstra

Just two years ago, adding a prescription drug benefit to Medicare seemed to be an idea whose time had finally come. These days, the issue is no less pressing, but it doesn't have the same urgency. Google "Medicare prescription drugs" and you will find a plethora of sites…but not much news since 9/11. Adding a drug benefit to Medicare is apparently one more casualty of that fateful day. On this issue, as on so many others, the Bush administration has stoked people's fear of terror and then used that fear to justify diverting national resources into massive military spending and away from dire social needs at home and abroad.

Melville G. Finkelstein's history of the Medicare and prescription drugs elsewhere in this issue is thorough and interesting for the background it provides. Mel says that the original 1965 Medicare proposal included prescription drug coverage, but this provision was eliminated due to potentially high costs. Why weren't price controls instituted at that time? Because the pharmaceutical industry didn't want them and they persuaded our lawmakers not to include them. They did this by pouring money into campaign coffers and paying lobbyists to apply unrelenting pressure.

Nixon's Congress also bowed to the pharmaceuticals and declined to add the benefit when it was reconsidered a few years later. The high cost of covering prescription drugs was invoked yet again when the short-lived Catastrophic Care Act was repealed in the late 1980s, under the first George Bush.

In each case compliant legislators eloquently opined on the tragedy of soaring prescription drug prices, and then quickly concluded that no pressure could be brought to bear on the pharmaceutical industry, and all cost increases would have to be borne by patients. The pharmaceuticals' winning strategy for four decades has been simply to purchase our government's agreement to protect their profits. They donate more to political campaigns than any other industry, and they spend more on political lobbying than any other industry. They've gotten a terrific return on their investments. Among other benefits, pharmaceuticals are one of the most lightly taxed of all major industries.

As Mel writes, the industry has been in league with the government agencies that are supposed to regulate it since those agencies were established. Mel understates the case, though, when he refers to the intense lobbying from the pharmaceutical industry as a mere "obstacle" to adding a prescription drug benefit to Medicare. It is in fact precisely this lobbying and the enormous financial power of the pharmaceutical industry in general that have blocked prescription drug benefits from the Medicare program at every step of the way. Given the history, it is difficult to conceive of our nation's politicians suddenly developing the willpower to threaten the most profitable industry in the country.

And for 20 years now the pharmaceutical industry has been *by far* the most profitable. Drug companies' profitability is now more than eight times the median for all companies in the Fortune 500, and more than three times that of other manufacturers of branded consumer goods. In 2001, while the overall profits of Fortune 500 companies declined by 53%, the top ten U.S. drug makers increased profits by 33%. The pharmaceutical industry ranked number one on all three of Fortune's profitability measures—return on revenues, return on assets, and return on shareholders' equity. And prescription drug costs went up another 20% that year.

Most Americans are by now aware that the industry is inordinately profitable and this makes them uncomfortable. Seventy-three percent of the American public thinks the pharmaceutical industry makes too much profit, with only tobacco and oil companies considered greedier. Why are companies that sell prescription medications the most profitable companies in America? Should aggressively marketing prescription medicines and then overcharging for those medicines be the road to riches?

Average retail prescription prices have doubled in the last ten years. Prescription drugs cost two to four times as much in the U.S. as in other industrialized nations, because the U.S. is the *only* industrialized nation that does not impose price controls on pharmaceuticals. Pharmaceutical treatments for the most common physical conditions average $20 to $90 a month, and the latest pharmaceutical treatments for depression can cost up to $300 a month. But not all drugs are average. The 29 biggest-selling drugs in the country (with more than $1 billion in sales each) comprise a full third of the U.S. pharmaceutical market. These

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Mel Finkelstein received his MA in Health Advocacy in May, 2003, and is currently seeking employment. He is interested in patient education and working with the elderly. ■

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drugs—the ones that are relentlessly advertised—cost an average of $97.71 for a month's supply in 2001, almost double the average prescription price.

More than half of all Americans and 85% of seniors have at least one regular prescription. Yet in 2003, one fourth of all Americans and more than a third of Medicare beneficiaries have no prescription drug coverage whatsoever. About a fourth of Medicare beneficiaries get coverage via their former employers as a retirement benefit, but more and more companies are dispensing with this benefit, citing costs. Only eight percent of Medicare beneficiaries have a Medigap policy that covers prescription drugs. These policies are simply too expensive for most seniors. For one thing, Medigap policies are written as individual policies, so they can't take advantage of group rates. And the premiums on certain Medigap policies, known as attained-age policies, increase with age. These policies are attractive to consumers because their initial premiums are lower than the rates on issue-age and community-rated policies, but this type of pricing hurts the people who need coverage most, the very old. The quickly rising premium rates on attained-age policies also hurt women disproportionately, since women make up three fourths of the over-85 age group.

About 17% of Medicare enrollees have some prescription drug coverage through Medicare managed care, but the scope of the benefits is rapidly declining. The remaining Medicare beneficiaries have prescription coverage through Medicaid or the Veterans Administration, eligibility for which is highly restricted.

Americans aged 65 and older now pay an average of $1205 a year each for prescriptions, and a Families USA study predicts they will be shelling out $2810 by 2010. Seniors comprise only 13% of the population, but they spend 42% of all money spent on prescription drugs.

Almost everyone who has prescription coverage is now enrolled in a so-called three-tier system, whereby generics, "preferred" brand names and other brand names carry different copayments. Copays range from $5 for a month's supply of a generic medication to $75 for a month's supply of a brand-name drug not on the company's preferred list. Other insurers cost-shift even further by dropping flat copays and requiring patients to pay a percentage of the cost of the drug instead.

It's all well and good to encourage a shift to generic drugs. Generics are certainly cheaper than their brand-name counterparts and their acceptance level among patients is high, but only about half of current drugs (none of the new, highly advertised ones) are available in generic form. Even when a generic is available, there may sometimes be valid reasons for particular patients not to switch from the brand-name drug, as in the case of a forgetful elderly patient who has come to recognize her various pills by color and shape.

Paying for prescription drugs is not just a problem for seniors. There are also 1.3 million non-elderly people receiving SSDI benefits (which include Medicare), many of whom desperately need prescription drug coverage. One third of these people are severely mentally ill. The high cost of prescription drugs is of course also a big problem for the uninsured, and it's even becoming a problem for workers who get coverage through their jobs and retirees covered by their former employers. These benefits are declining everywhere, even as the costs of prescription medicines soar.

Right-wing ideologues such as the editors of the *National Review,* say that health care costs rise as rapidly as they do because Americans pay for their health care mostly indirectly, so they have no incentive to control costs (*National Review* 2002). They say letting government pick up the tab (as through the Medicare program) only exacerbates the problem. But this is not why prescription drug expenses are rising so rapidly. Much more important is the fact that the population is aging, and older people have more chronic conditions that require constant medication.

Costs are rising as well because U.S. pharmaceutical companies routinely overcharge domestic customers for their medications; this is the only rich country in the world that allows them to get away with it. The pharmaceuticals charge Americans an average of two to four times what people in other industrialized nations pay for the same drugs; they have purchased the privilege to do so by contributing massively to the political campaigns of virtually all the key decision makers in Washington, who reward them by graciously refusing to regulate them. They secure the privilege by employing an army of 625 registered lobbyists, paid an average of $144,000 a year, to keep the pressure on 535 Members of Congress.

What do pharmaceutical lobbyists lobby for? They lobby to keep or move as much of the system as possible into private hands. They lobby to hang onto patent rights, to bar cheaper generics from the marketplace. And as they lobby they hide behind fake grassroots groups whose names betray their funding by the industry. A typical example of these is Citizens for Better Medicare, a group devoted to privatizing Medicare. The group is funded and run entirely by drug companies but bears a name that sounds like "just folks." In the immortal words of Jim Hightower, "How many legs does a dog have if you count its tail as a leg? Four. Calling a tail a leg doesn't make it one. Neither can 'Citizens for Better Medicare' be counted as a grassroots group just because its organizers call it one" (Hightower 2000).

From a medical standpoint, also contributing to rising costs is the fact that, over the last 40 years, prescription medicines have become the treatment of choice for many conditions that used to require surgery or were simply untreatable. In mental health, prescription drugs have to a great degree supplanted extended sessions of psychotherapy, because the drugs are often more effective and almost always cheaper.

From a cultural point of view, Americans have come to expect prescriptions from their doctors. The little piece of paper that turns into the little brown bottle is our marching orders, our game plan for fighting what ails us, our secret weapon (all military metaphors!). This is something that can and should be changed where possible. It is widely known that many of our chronic afflictions are caused and/or worsened by our own unhealthy behaviors. Many Americans could certainly reduce their own prescription drug costs by making lifestyle adjustments, but the cultural preference is for the quick fix, and that preference is relentlessly exploited by the drug marketers.

Perhaps the biggest reason more and more prescriptions for pricey, patent-protected drugs are written is that the

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pharmaceuticals are so aggressively marketing their products to patients and doctors. Advertising costs have risen exponentially since the industry was first allowed to advertise directly to consumers (DTC) in 1997. The airwaves are increasingly dominated by ads pushing the latest pill or patch, most typically for ailments that disproportionately affect middle-class, insured people: headaches, allergies, hair loss, hypertension, obesity, incontinence, impotence, depression.

Pharmaceutical companies increased their spending on consumer advertising from virtually zero in 1997 to $2.6 billion in 2001—that's four quick years. The results of that spending are all over your TV screen. And every ad contains the phrase "Ask your doctor about ...." Sometimes the companies make it even easier. The heartburn medication Nexium is aggressively marketed by AstraZeneca as "the purple pill." Its web site is even at *purplepill.com*, so folks suffering from heartburn don't have to remember the brand name, they can just ask their doctor about "the purple pill." Perhaps Barney should be AstraZeneca's spokesperson to reinforce the visual cue.

Many studies have shown that DTC ads encourage consumers to demand brand-name products from doctors and that doctors are influenced by these demands, sometimes prescribing requested medicines despite their personal ambivalence. Research undertaken by Harvard and Harvard Pilgrim Health Care (*New England Journal of Medicine* 2000) has also found that consumers cannot assume the news media will offer an impartial view of new medications. Only about a quarter of articles reviewed mentioned the risks associated with the new drug, and only about a quarter mentioned the cost. And in fully half the articles which cited an expert or a scientific study, those experts or study investigators had financial ties to pharmaceutical companies that stood to benefit from a favorable assessment of the product.

In an interview last spring (*AARP Bulletin 2002*), Dr. Robert Goodman, assistant professor of clinical medicine at Columbia University, said that DTC advertising has made many people think that expensive, patent-protected Celebrex from Pharmacia and Merck's Vioxx are more effective at treating pain than ibuprofen, available in over-the-counter remedies like Motrin and Advil. "That's absolutely not true for pain," says Dr. Goodman, and moreover, Celebrex and Vioxx are the same in their effectiveness, "so the only way drug companies are going to get physicians to prescribe Celebrex over Vioxx or vice versa is to out-promote the other guy." Or maybe the drug with the most Xs in its name wins….

People are bombarded with these ads, especially the elderly, who in our society often live isolated lives and keep their TVs on for company. Meanwhile, highly aggressive and/or seductive salespeople from the pharmaceutical companies pound the pavement providing doctors with everything from free pens and notepads to generous product samples and all-expense-paid junkets to exotic locales. These are generally touted as "continuing education" seminars, but in reality they are extended live infomercials for particular drugs. Through DTC advertising and relentless pitching to doctors, the pharmaceuticals create a market of people primed to ask for particular drugs and a critical mass of doctors primed to prescribe those drugs.

The pharmaceutical industry has always claimed it needs high profits to finance research and development, but the facts belie these claims. In 2001, Fortune 500 drug companies channeled only 12.5% of revenues into R & D, while profits were 18.5% of revenues. In fact, taxpayers directly and indirectly sponsor most pharmaceutical R & D programs through generous tax credits and government grants awarded the companies. The argument that price controls will stifle pharmaceutical R & D is simply a nonstarter, though the industry has achieved great success in planting this worry in the public mind. Sixty percent of Americans think there should be more regulation of the pharmaceutical industry, but this figure drops to 42% when respondents are asked to consider that such regulation might lead to less R & D.

The truth is the industry needs high profits to continue to channel huge amounts of money into political campaigns and insure the election of politicians favorable to its agenda and beholden to its purse. And it needs high profits to maintain the army of lobbyists who keep the politicians reminded of their obligations.

Families USA has unequivocally rejected the Bush Administration's latest plan for adding a prescription drug benefit to Medicare. That's because Bush's plan fundamentally coerces seniors into leaving traditional Medicare and joining private health plans as a condition for receiving prescription drug coverage. Those who choose to remain in the traditional Medicare program (which now covers 89% of Medicare recipients) will not get their prescriptions covered.

As Families USA Director Ron Pollack notes, "Private health plans participating in Medicare have a poor record serving seniors. They are unavailable in rural communities, and they frequently leave communities that are deemed unprofitable" (Families USA 2003). Pollack predicts that the Bush camp's linking of prescription drug coverage to enrollment in private health plans will make enactment of any prescription drug coverage in this Congress "a Himalayan expedition."

Mel says public demand alone makes a Medicare drug benefit probable, and we can only hope he is correct. More than 90% of Americans report they take prescription drugs. More than half take them on a regular basis, and more than one fourth take three or more drugs regularly. Our government, which gutlessly left prescription drugs out of the original Medicare bill and has gutlessly refused to deal with the issue for four decades, faces a public increasingly reliant on the drugs and increasingly unable to pay for them. It's an untenable situation.

I do not believe, though, that Republicans and Democrats need only iron out the details and we shall have a Medicare prescription drug benefit. Neither party

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Congratulations to HAP Graduates !

December 2002

Ethlouise Banks
Carol Fleming-Huskisson
Desiree C. Perez-McDougall

June 2003

Melville G. Finkelstein
Chris Fulton
Jaime Lobb
Deirdre A. Macho
Farrah S. Schwartz

Humanizing Cancer Treatment: Patient Advocates Can Make the Difference

By Casey Warren MacDonald

If presented with a cancer diagnosis, would you know what to do? Where would you turn for guidance to make the necessary decisions for treatment and, one hopes, recovery? According to the National Cancer Institute, one in three people will be diagnosed with cancer in his lifetime, for most, a terrifying moment. A common reaction is shock and disbelief, making it difficult to comprehend or process information from the doctor. Lack of information and understanding of medical jargon are only two obstacles to patient care, however. A cancer patient is thrown into the medical web of navigating appointments for blood work, biopsies, scans, chemotherapy, radiation, seed implants, transfusions and on and on. The process can be overwhelming. Add to that the daily demands of work, family and the overlooked psychological process of coping with a life-threatening illness. It quickly becomes apparent that these patients need support and guidance. From coast to coast, cancer centers are finally acknowledging the extreme stresses that cancer patients face and are working to bridge the gaps in care and communication through patient advocacy programs.

Many cancer centers in the United States have added patient advocates to their staffs. In a majority of hospital oncology departments, new admissions are greeted by an oncology social worker who works with the patient and family to explain the hospitalization process and address their needs. Most cancer patients are not hospitalized, however, and many centers do not provide social workers for patients treated in an ambulatory setting. Even if a patient is receiving radiation or chemotherapy in a separate area of the hospital, there is usually no one to provide assistance. Two of the country's comprehensive cancer centers committed to offering premier cancer care have filled this need by providing patient advocates for both inpatient and outpatient cancer patients. The University of Texas M.D. Anderson Cancer Center and the Barbara Ann Karmanos Cancer Institute in Detroit, Michigan, have answered the call to meet cancer patients' need for guidance, information and support, each in a very different way.

M.D. Anderson—A professional model

The University of Texas M.D. Anderson Cancer Center, located in Houston, is part of the Texas Medical Center and connected to the University of Texas. In 1941, the Texas State Legislature created the hospital as a public facility to treat cancer and linked it to the University of Texas for study of the disease. Today, it is ranked by *U.S. News & World Report* as the nation's number one hospital for the treatment of cancer. Its name comes from wealthy businessman Monroe Dunaway Anderson. In the 1930s, Anderson created a charitable trust with about $300,000; at his death in 1939, the trust received close to $19 million. The trustees made a deal with the Texas Legislature. They would give $500,000 to establish the hospital for cancer research with the stipulation that it be built in Houston.

The center concentrates solely on cancer, no other diseases. The12-story hospital, known as the Albert B. and Margaret M. Alkek Hospital, houses a fraction of the organization's 12,700 employees. M.D. Anderson is also the country's top facility for cancer research. Known for its cutting-edge research and innovative clinical trials, Anderson treated 60,000 individual patients and had more than 471,000 outpatient visits, treatments and procedures in 2002. The center operates on a whopping $1.4 billion budget.

Although designated by the National Cancer Institute as the nation's leading hospital, it does not resemble a hospital. Aquariums are strategically placed for visual comfort and there is a piano player in the food court. The hotel-esque atmosphere in the vaulted ceiling lobby is calm, creating a soothing atmosphere upon arrival. Every patient is welcomed by a volunteer greeter and shown to the appropriate area. The goal is to make each detail of the process as easy as possible.

M.D. Anderson Cancer Center has what every cancer center in America should have—a paid, professional advocacy program. Its advocacy department consists of trained patient advocates dedicated to ensuring that the cancer journey at M.D. Anderson offers abundant compassion and minimal confusion. The advocates at Anderson are part of the medical team, but not involved in the treatment process. Available 24 hours a day, seven days a week, they are a voice for the patient, a bridge of communication between patient and clinicians.

When a patient makes his initial visit to one of the 27 treatment centers, an advocate introduces herself, explains what services are available and describes her role as liaison. If the patient has a complaint or concern but is uncomfortable discussing it with his physician, his advocate can speak on his behalf. In addition to creating a smooth course of treatment, advocates help with scheduling difficulties, billing questions, referrals to other professionals on the medical team and problems regarding staff or excessive wait times.

Patient advocates are trained for four weeks, shadowing each of the veteran advocates for two days. This method enables them to understand each treatment center and observe their colleagues' responses to various situations. Each advocate is assigned 15-20 on-site patients every day and receives 10-15 phone calls from patients, which are expected to be returned the same day. Whether the patient becomes an inpatient or outpatient, whenever he returns to M.D. Anderson, he retains the same advocate. Advocates are also walking directories, knowledgeable about patients' rights, hospital policies, specifics about each center and all of the services provided at Anderson. They can provide information on activities, support groups, the cafeteria and hotel, the patient library, religious services, assistance for international patients and much more. "Patient advocates personify what is best at M.D. Anderson Cancer Center," says Dr. Charles Levenback, associate professor of gynecologic oncology.

Although Anderson has fewer than 25 professional patient advocates, they are supported by an army of 1,400 volunteers who logged more than 270,000 hours in 2002. Known by the blue coats they wear, the volunteers span ages 13 to 94, operating in all areas of the hospital, including the gift shops, beauty/bar-

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Humanizing Cancer Treatment

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ber shop, Business Center, Patient Family Library and Patient Family Center. They can be found at the Concierge & Information Desks or delivering flowers, giving tours or arranging religious services. Many spend one-on-one time with patients and their families. Pediatric patients benefit when volunteers help with homework or plan birthday celebrations. The blue coats are even valued in research departments, performing technical tasks such as cutting chromosomes. M.D. Anderson has taken volunteerism to extraordinary heights in its quest to provide exemplary cancer care. While the volunteer provides many worthwhile traveling aids for patients on their cancer odyssey, it is the professional advocate who provides the map to ensure an informed and educated journey.

The Barbara Ann Karmanos Cancer Institute—a volunteer model

The Barbara Ann Karmanos Cancer Institute, cited by *Modern Maturity* in 2001 as one of the nation's 15 "Most Friendly" medical centers, lives up to that designation. Located in Detroit, it received its name in 1995 after a $15 million dollar donation from Compuware founder Peter Karmanos in memory of his wife, who died of breast cancer in 1989. It is the only major cancer center in the United States named for a woman. The Institute operates the Meyer L. Prentis Comprehensive Cancer Center and is partnered with Detroit Medical Center and Wayne State University. The hospital opened in 1935 as the Women's Field Army Hospital, which it remained until 1943, when it became the Detroit Institute for Cancer Research. It was renamed the Michigan Cancer Foundation in 1966 and merged with Detroit Medical Center in 1994. Wayne State University also became part of the medical center the same year.

Although the Barbara Ann Karmanos Cancer Institute functions on a smaller scale than M.D. Anderson, it is still impressive. Also an NCI-designated hospital, it has 1,200 employees and treats more than 10,000 new patients with over 96,000 outpatient visits a year. Operating on an annual budget of over $200 million, it receives approximately $40 million in research grants which help fund various clinical studies.

What truly distinguishes this cancer center, however, is its all-volunteer patient advocacy program. Led by Patricia Fadell, Director of the Clinical Volunteer Support Program, the 364 volunteers are known as navigators. They guide cancer patients through the treatment web with compassion, empathy and kindness. Coming from various segments of the community, the volunteers include retired seniors, college students, former cancer patients and their families. Their primary goal is to make patients as comfortable as possible while trying to lessen the anxiety and fear that so often accompany the cancer diagnostic and treatment process. It is perhaps the best example of a volunteer cancer advocate program in the country.

The mission statement of the Volunteer Support Program of the Institute is straightforward. The program "offers an extra and vital dimension of care, education and service to cancer patients, empathy and assistance for families and visitors and supportive service for the Karmanos Cancer Institute staff and community." The navigators at Karmanos Cancer Institute perform a special and necessary function, "caring services," for each cancer patient. Before a patient's initial appointment at any of the Institute's locations, the Volunteer Support Department calls to inform her about the navigator program. When she arrives, a navigator guides her from the first step in the process (registration) to the next (x-ray) and so on until completion. He shows the patient where to check in and where the waiting rooms are located. Often, navigators provide a tour, pointing out restrooms, pay phones, the cafeteria, pharmacy and the Education and Resource Center. They can provide maps to various clinics at the Institute or personally escort the patient to an appointment. They offer amenities such as tea or coffee (and Kleenex) and can help the patient organize questions to ask her doctor. They are the link between hospital and patient, a resource upon which the center depends to relieve the stress and anxiety of the cancer experience.

When a person decides to become a navigator at the Barbara Ann Karmanos Cancer Institute, he is asked to fill out a questionnaire explaining why he wants to undertake this role. Training involves a seven-hour session, which includes learning what he may and may not do. Navigators are not permitted to give medical or legal advice or to involve themselves in family decisions. They may not approach doctors regarding the medical care of any patient or interfere in any way with that care. Navigators are also advised not to share personal experiences. They are trained in cancer definitions and pronunciations and can assist patients in researching their condition. They receive extensive training in communication methods, including the SOLVER Method: **S**quarely facing the other person, **O**pen posture, **L**ean forward, **V**erbally follow, maintain **E**ye contact and be **R**elaxed. Each navigator receives a handbook with various "what-if" scenarios as a reference.

Navigators are assigned to 15 locations throughout the Institute, including the Wertz Clinical Cancer Center, which is the primary outpatient facility for chemotherapy and blood transfusions. They are also assigned to the Gersheson Radiation Oncology Center, home to cyclotron and neutron therapies, one of only two such sites in the United States. Other placements for navigators include the Education and Resource Center, the Breast Center, the Call Center, Patient and Family Support Services and Medical Records. Once a navigator's responsibilities with his patient are fulfilled, he aids the clinical staff whenever possible. Navigators are utilized by the staff to retrieve medical charts and x-rays and in other non-medical functions.

Both the M.D. Anderson Cancer Center and the Barbara Ann Karmanos Cancer Institute are special because they provide what is sorely lacking in today's modern medical establishments: advocates who play a pivotal role in providing a human connection for patients dealing with cancer. Whether paid or volunteer, each program supports the cancer patient and reduces the anxiety inherent in the cancer experience. The goal of each organization is to navigate the patient through the medical web in a seamless transition from diagnosis to treatment. The presence of someone to assist in even the smallest details can bring comfort to a worried patient or family member. Two of the nation's top cancer centers have recognized the patient's need for personal support and caring when coping with cancer and have created excellent models of patient advocacy.

Casey Warren MacDonald is a mother of two, cancer survivor, graduate student at Sarah Lawrence College and HAP 2002 Porrath Fellow. ■

SHCA Convenes in Washington, D.C., for its 32nd Annual Conference

By Lucy Schmolka

Their numbers may have been down, but their spirits were high, as 156 members of SHCA (pronounced SHUH-CUH) convened April 25-28 in Washington, DC., at the Society for Healthcare Consumer Advocacy 32nd Annual Conference and Exhibition. It was a chance to pick up information and insight from experts, to share problems and successes with colleagues, and to celebrate and reaffirm a common commitment to improving the health care experience for all. From Wendy Leebov's deeply moving and highly personal opening remarks on humanizing the patient/family/provider relationship to Liz Jazwiec's frank (and very funny) closing address examining pitfalls and strategies in improving patient and staff satisfaction, there was energy and excitement as attendees both acknowledged the obstacles and determined to overcome them. They also had a good time.

This year's theme was "One United Voice Capitalizing on Knowledge." Responding to requests by prior participants, seminars were divided into two tracks, fundamental and advanced. The fundamental track covered creating a customer-focused culture, ensuring equal care for patients with language barriers, advance directives, service recovery, informed consent, patient satisfaction, dealing with difficult people and how to survive in times of change. Advanced participants discussed handling unexpected outcomes, helping patients navigate safely through the health care system, grassroots advocacy, applying web-based resources, creating a culture of safety, using the Health Assistance Partnership, educating patients on how to take charge of their healthcare decisions, and confronting the problem of medical errors. Among the faculty were many practicing patient representatives, but speakers were as diverse as professional risk managers and a professor of health policy and administration.

Additional program options included a pre-Conference session on April 25, a Canadian networking session, a post-Conference session for VA Hospital representatives, and an opportunity for all SHCA attendees to participate in American Hospital Association (AHA) programs, activities, and Capitol Hill visits after the SHCA Conference ended. A special "bookstore" offering advocacy-related materials was open through much of the Conference, as well as an Exhibit Hall where companies promoted programs and equipment to attendees.

Registrants represented 107 different hospitals from 24 states, plus Canada and the Philippines. For 34, this was their first SHCA Conference. Most of the attendees were hospital-based patient representatives. Many came from small or single-person departments. Ellen Moscinski, from the Maine Medical Center, was a walk-in registrant who only a week before had been charged with adding patient advocacy to her portfolio as Director of Social Work. In charge of the newly named Patient and Family Services Department, she was looking for "practical tools" and an opportunity to network. She found both, but also "at once felt a new, healthy and supportive professional group had accepted me."

Others have been attending the Conference for as many as 20 years. Aside from camaraderie and support, they hoped to fine-tune their skills and update their information base. As Moscinski observes, "Both newcomers and seasoned advocates mixed and fed off each others' ideas."

At the Business Luncheon, there were remarks from President Lisa Reynolds, reports from the various work groups, and the presentation of APEx awards in recognition of professional excellence and the Ruth Ravich Founders Award for outstanding achievement in promoting SHCA's vision of patient-centered advocacy. The last went to Anita Woodward, a former patient representative who, after 18 years in hospital-based patient advocacy/customer service and, armed with a new MBA, recently started her own consulting business.

Woodward 's first Conference was in 1984, after which she rose through the ranks, becoming president in 1995. "Without SHCA, there would be no good place for advocates to come for networking, education, renewal and inspiration," she says. "I've met many wonderful people…gained wisdom, knowledge, and friendship...and had a lot of fun—all while doing things that I believe benefit the patients by making the system a more humane one for them."

On a less positive note, Glen Brown, SHCA's new Executive Director, reported that current SHCA membership is 806, down from 869 in 2002, 909 in 1999. Conference registration has dropped from 200 in 2002, 241 in 1999. The rallying cry: raise the membership so we can raise our impact.

Initially called the Association of Patient Representatives, SHCA was established in 1971. Founder Ruth Ravich, a pioneer in hospital-based patient representation, served as its first president. One year later, it affiliated with the AHA and became the National Association of Patient Representation and Consumer Affairs. Its most recent name change occurred in 1997, the result of a decision to reflect an expanded advocacy role which encompasses all healthcare consumers, not just hospital patients, and to reach out to other healthcare consumer advocacy professionals and organizations.

SHCA's current goals: to advocate for public policies that are in the consumer's interest, to enhance professional development of healthcare consumer advocates, to strengthen the role of the profession in healthcare delivery system improvement, and, in order to meet these objectives, to maintain a healthy financial and organizational infrastructure. Especially exciting to its leadership is SHCA's current collaboration with the AHA in the Patient Care Partnership, a global campaign to inform AHA members of their revised and expanded "Patient's Bill of Rights."

Looking ahead, Reynolds is both enthusiastic and ambitious: "As an organization, we want to continue to educate our members so they can provide leadership and value to their institutions. We also want to be recognized as experts on patients' rights, service excellence, customer service, ethics and patient satisfaction. This will be done through our web site, educational offerings and work group projects. We look forward to collaborating more with other organizations and building name recognition for our profession and the society."

The relationship between SHCA and HAP dates from the latter's inception. Building on the growth of the patient representation movement and the success of the Society, Ms. Ravich joined with Joan Marks to create the SLC Master's Degree Program in Health

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From the Ethics Files

This feature highlights cases that present unusually difficult ethical issues. Readers are invited to respond to the questions raised by email: health@slc.edu.

By Alice Herb

A baby girl born at 22 weeks gestation, weighing 15 ounces, was admitted to a Neonatology Intensive Care Unit. She had confounded clinicians when she remained alive in spite of her extreme prematurity and extremely low birth weight. At 19 days, the infant still had the same weight and had suffered Grade IV hemorrhages and PIE (pulmonary interstitial emphysema). On the positive side, she had managed to open her eyes. Her prognosis was extremely bleak.

The neonatologists and nurses agreed that, given the baby's history, there was little doubt that the infant had been severely compromised but the mother insisted that this baby would grow up just like her other child who had weighed little more than a pound at birth and was now fine.

At the first ethics consultation, the baby's "best interest" and the principle of "do no harm" were discussed. The clinicians concurred that, until this point, the baby had not been harmed. However, an important issue for the physicians to address was how aggressive and invasive treatment should be. The physicians were willing to comply with the mother's wish to resuscitate the infant if her heart stopped or if she stopped breathing. But if resuscitation attempts appeared to be failing, the full resuscitation procedure would probably be discontinued. The futility definitions under the Do Not Resuscitate (DNR) law were reviewed and it was agreed that the attending physician would talk to the mother about a DNR order again. He was certain she would refuse to sign a DNR but if the infant survived, he would be firm about the futility of continued treatment.

A month later, the infant was still alive, once again had sustained significant cerebral hemorrhages, but appeared to be getting better. For the physicians, "better" did not mean that the prognosis had changed. Her lungs and her heart had continued to develop, but the bleeds had caused serious neurological damage. The baby, if she survived, would undoubtedly be profoundly retarded among other serious medical problems.

At the second ethics consult, the physicians expressed their concern that aggressive treatment at this point might indeed begin to "do harm." Now, however, psychosocial issues began to affect medical decision making. The father, on each occasion when he did visit, appeared to be drunk. He demanded that "everything" be done and rejected the poor prognosis. The mother seemed afraid to disagree. There was some indication that the premature delivery was caused by domestic violence, suggesting that each parent had his/her own agenda—most likely having nothing to do with the infant's "best interest."

The recommendation to the providers after this consult was that further meetings with the mother and/or both parents were essential. Physicians had to make further attempts to explain the severity of the infant's condition. If the mother or both parents continued to demand aggressive treatment, whenever the next inevitable crisis occurred, the physicians would have to decide whether continued treatment was appropriate. A DNR discussion was now no longer critical.

Yet another ethics consult occurred a month later. The baby had continued to do well physically. She was now on tube feeding but remained on the respirator. Providers were continually reminding Mom that there was no chance that the baby had *not* been neurologically damaged. Moreover, the baby might continue to linger but there was virtually no possibility that she would even survive to go home. Mom refused to hear and Dad, when he came, would not talk about it.

Discussion led to a consensus that physicians should order a CT scan to attempt to assess the baby's neurological damage. Then, with this test in hand, clinicians should confer with the Mom again, state clearly to her the baby's best interest and explain to her the appropriate care plan to be put in place—one that would be palliative in nature. It was also noted that there was little hope that either the mother or father would listen and change her/his mind. It would therefore be incumbent on the clinicians to document fully all the consultations and family meetings and to proceed with treatment that was in accord with the principles of *beneficence* and *non-maleficence*.

This is the sort of case that can drive clinicians and even ethicists to distraction. A baby so premature and of such low birth weight is not supposed to survive. Yet against all odds, once in a while, these tiny beings, who ought not to be viable, fight to live. Such medical anomalies make it easy for us who are not medical professionals to shrug off diagnoses and prognoses and root for the baby. We think that, having survived, she will end up going home and end up just fine. But that is almost never the case. Even under the best of circumstances, these neonates have a tough time. Setting physical problems aside, early interventions, special education and the like help but are usually not enough to compensate for the serious damage sustained.

We also assume that mothers and fathers want the best for their babies, the reason why they are empowered to make medical decisions for their children. But this right to decide is not absolute. When it becomes obvious that the parents are making decisions that are not of benefit but indeed even harmful, clinicians have an obligation to advocate for their tiny charges and treat appropriately.

This situation appears to be even worse. The baby's predicament may in fact be due to the father's abusive behavior to her mother. Without the mother's cooperation, however, it is impossible to report to the authorities vague allegations that may even place the mother at greater risk.

Caring parents who want the best for their babies are often prone toward demanding all treatment, when ratcheting back is the best course for the infant. They may be wishing too hard or have other understandable reasons why the bad news is so hard to accept. These parents too need long and patient treatment so that they may slowly begin to grasp their situation. Of course there are always those very few that do survive and make it all the more difficult. But not at 22 weeks gestation and weighing less than a pound.

Alice Herb, JD, LL.M., is a member of the Health Advocacy and Human Genetics faculty at Sarah Lawrence College. An attorney and bioethicist, she teaches bioethics to graduate students at SLC and to medical students at Downstate Medical School (SUNY). Her interests include human subject protection in research and end-of-life decisions. ■

From the Director...

By Marsha Hurst

Frankly, as I sat down to write this letter I was focused on how many critical health policy issues were in the news once again (having been pushed to the background by the Iraq war). SARS, of course, reminds us that epidemics are still about politics and economics, the connections between peoples of the world, travel and commerce, and about effective and humane systems of public health. In October, Laura Garrett spoke at Sarah Lawrence College about the failures of public health around the world. This came to mind as I read that in Russia 1.47 million people today may have HIV/AIDS, and that number could rise to over seven million, or one in four, within five years.

At home we are fighting renewed battles over coverage and access to care as attempts to privatize Medicare loom large once again. This issue features two articles about the issue of prescription drug costs, just as the Supreme Court ruled that Maine is allowed to proceed with its plan (enacted in 2000) to lower the cost of prescription drugs for State residents. What is that old political saying? As Maine goes, so goes the nation.

As the economy has declined, the prospect of being uninsured looms larger. Recent studies found that, while 41 million Americans may not have health insurance at any one point in time, 75 million did not have health insurance for some part of the last two years (www.familiesusa.org). Nearly 20 percent of college graduates and 50 percent of high school graduates do not have health insurance. Yet access is critical to health. A study in *JAMA* (May 21, 2003) reported that access to health insurance "could largely close the racial gap in medical care and survival rates" for African-Americans with heart failure. The Democratic presidential race seems to be increasingly focused on candidates' plans to increase health coverage, although the front-runners shy away from any straightforward single-payer system.

Yet there are recent small victories. The Genetic Information Nondiscrimination Act of 2003, a six-year-old legislative initiative to prohibit employment discrimination on the basis of genetic information, passed the Senate Committee on Health, Education, Labor and Pensions (May 21, 2003). The National Partnership for Women and Families led the advocacy coalition for this bill. Judith Lichtman, the Executive Director, and members of her staff have been guest speakers in our Models of Advocacy course, giving students and faculty an insider's view of legislative advocacy in D.C. On the international front, the World Health Organization passed the Framework Convention on Tobacco Control to reduce tobacco consumption around the world.

In the Health Advocacy Program, we have been working to connect the larger policy issues with individual experiences and needs. In our course on "Illness Narratives," first-year students explore their own experiences, interview patients and read the rich literature of published narratives. At the faculty retreat—a discussion session that precedes our June faculty meeting—we will be focusing on the theme of "The Concept and Use of 'Voice' in Health Advocacy," exploring "voice" across our disciplines, in direct and indirect advocacy.

Sayantani DasGupta and I are working on two academic projects: a book, *Stories of Illness and Healing: Women Writing their Bodies*, still in the proposal stage, and a paper on "Women's Illness Narratives and the Humanization of the Health Professional" to be delivered in Oxford at an interdisciplinary conference on "Health, Illness and Disease" in July. Our paper will explore how women's illness narratives can be used in the education of health and medical professionals to enhance their understanding of the patient's experience and the contextual meaning of illness itself. Alice Herb, Abbey Berg, a pediatric research audiologist, and I are writing a paper on "Cochlear implants in children: Ethics and advocacy revisited." This has been a wonderful opportunity for a three-way dialogue on very complex ethical and advocacy issues surrounding medical technology, deafness and Deaf culture.

These interdisciplinary explorations have been encouraged by our participation in the Health, Science and Society (HSS) faculty group at SLC. Three Health Advocacy students took the new fall 2002 cross-registered course I taught with Karen Rader (Science, Technology and Society), "Women and Health: Beyond Our Bodies Ourselves" (pages.slc.edu/~krader). The HSS faculty group intends to explore the meaning and impact of the genetic paradigm in a workshop this summer and to host a speaker series beginning in the fall (watch for it on our web site, www.slc.edu/~health). Interdisciplinary collaborations with College programs have also resulted in two Theatre-Health Advocacy staged readings followed by panel discussions: *W;t* (spring 2002) and *A New Brain* (May 2003). Shirley Kaplan, Director of the SLC Theatre program, and Alice Herb, our HAP ethics professor, participated in both panels, joined by other faculty members and advocates. We are excited about future collaborations.

We will report in a later issue on two community-based initiatives. In February, the Health Advocacy Program, Yonkers community groups and health providers, the Westchester Public Library System and other organizations held a conference on "The Literacy Crisis in Healthcare: A Community Response to a National Challenge." (See the Spring 2001 *Bulletin* for our study of "Health Literacy and Advance Directives.") The second initiative is a new Westchester End-of-Life Coalition, an outgrowth of

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From the Director

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the series "Understanding the End-of-Life" co-sponsored last year with the Jansen Memorial Hospice. The Coalition is a member of Rallying Points (rallyingpoints.org), a Robert Wood Johnson initiative to encourage community-based end-of-life coalitions. We will report on a web site and further progress in the Coalition's work in the next issue.

We began with some international health issues of concern to advocates. Let me end by noting some changes in the Health Advocacy Program. Last fall we piloted two building-block courses in Health Advocacy. Diane Borst taught a half-semester course on the "Health Care System" and Laura Long, new to Health Advocacy but a graduate of and instructor in Human Genetics, taught a workshop the other half of the semester on "Communicating with Patients." Students thus started off with the big systemic picture and the smaller direct advocacy skill, both critical to their advance course work and fieldwork. Laura's course is described in this issue.

And, finally, I would like to welcome our new editor of the *Health Advocacy Bulletin*, Lucy Schmolka, HA '90. Lucy spent nine years as a patient representative at Mount Sinai Hospital in New York City, and also taught in the core course in the Health Advocacy Program. We are all really pleased that Lucy agreed to become the new *Bulletin* editor; this issue speaks for itself in terms of her abilities and her commitment to the field of Health Advocacy. Welcoming Lucy means I must acknowledge the loss of Deb Hornstra, our previous editor. It was wonderful working with Deb; as you see by her contribution to this *Bulletin*, she has stepped aside but not away. Thank you Deb for past editing and for future—we'll count on it—writing. ■

SHCA Convenes

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Advocacy in 1980. Since then, many HAP graduates have become involved in SHCA activities, with graduate/faculty member Laura Weil currently serving on the Board. In fact, Sophie Seniuk, 1990 HAP graduate, won this year's SHCA Conference grand prize drawing, a trip to Hawaii.

SHCA can be contacted via its web site, www.shca-aha.org. ■

No Medicare Prescription Drug Benefit

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is committed to reducing the influence of the pharmaceutical companies or increasing the power of consumers to purchase prescription drugs at affordable prices. No Medicare prescription benefit will be enacted by this Congress.

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A complete list of reference material for this article can be found at the HAP web site.

Deborah Hornstra, HA '97, is a communications consultant in Princeton Junction, New Jersey. She designed web sites for the HAP and the New York Society for Healthcare Consumer Advocacy and was formerly editor of the Health Advocacy Bulletin. *Most recently Deb developed Internet promotional strategies for the bestseller* The Best Democracy Money Can Buy *by Greg Palast. She can be reached at* deb@hornstra.net. ■

Ed.: As we go to press, there is talk of a bi-partisan Senate bill offering Medicare prescription drug coverage. We will watch its progress with interest.

Treading Firmly Through the Medical Minefields

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feeding, occupational, physical and psychological therapies. Advocating for a child with behavioral challenges and emotional depression is exasperating. No one pointed a finger of blame at me when I was advocating for Molly. But the families of children with behavior and mental health problems are seen as the *source*. Jacob has a scatter of skills—some very age-appropriate, and others that are quite substandard.

Because Jacob is so intellectually curious, school administrators want to maximize his academic knowledge. My new husband and I, on the other hand, believe that life skills are what get you through life. We strongly feel that Jacob has to be able to be polite, follow directions and complete his own ADL's (activities of daily living), such as bathing, toileting, feeding, etc. A successful adult has to know how to cross the street, looking both ways for oncoming traffic. I have worked very hard to design school programs that include life skills. His school district and I have created a summer program where he will perform community service, tasting different jobs in our local park system. I'll send along an aide to assist as a job coach. This coming September, Jacob will enter a school that focuses on life skills.

Three years ago, my new husband Darryl became ill with a rare cancer. Advocating for a spouse is quite different from acting on behalf of a child. My input was more behind the scenes. A spouse is invisible, except when s/he is being difficult. I never wanted to be difficult. After all, the doctors and nurses were trying to save Darryl's life. Add subterfuge to the list of necessary skills. My husband survived chemotherapy and three stem cell transplants. He's back at work, and I've gone back to finish my undergraduate degree. I've enrolled at Sarah Lawrence, and maybe this time I'll finish.

I've included some of my favorite resources in this article (see box on page 5). I have also shared a few of the health forms I've written for families to use; links to these forms can be found on the HAP web site.

Maggie Hoffman, happily married to her husband Darryl, has two delightful children, Jacob and Rosie, and an energetic Labrador named Daisy. She currently is working with Project DOCC in partnership with the United Hospital Fund, utilizing her extensive experience with chronically ill and developmentally disabled children. ■

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