



### // MISSED THE LAST ISSUE?

All stories from *Proto*, Fall 2009, are available at [protomag.com](http://protomag.com).

## Almost Blackmail?

While I sympathize with physicians who encounter a “patient from hell,” I cannot fathom asking patients to waive their right to complain about their physician on online review sites, a practice Jeffrey Segal champions (“Don’t Tread on M.D.,” Fall 2009). It may not be outright blackmail, but the still-godlike status of M.D.’s makes patients reluctant to disappoint their physician by not signing such an agreement.

Sadly for Segal, empowerment of the public is the dominant paradigm of our age. Traditional boundaries and power structures are being displaced, including those within medicine. Segal represents the “lawyering” of the medical profession, which focuses on physician liability at the expense of effective or innovative treatments.

Few people select a physician based on Web sources, making Segal’s idea of forbidding patients to post to online review sites (except those he has approved) both philosophically and practically a nonstarter. His plan may even be unconstitutional as it seeks to limit speech—a limit that custom and professional courtesy have provided to physicians for hundreds of years. “Doctors bury their mistakes,” we used to say; that era is ending. This is the era of the informed, self-aware patient. Online feedback is part of this new world, in which heightened accountability of treatment providers—who will have the occasional “difficult patient”—is the norm. Segal doth protest too much.

**Dag Spicer** // Santa Clara, Calif.

## A Need-to-Know Basis

In her essay “Choosing Chance” (Fall 2009), Betsy Wiesendanger recounts her decision not to undergo BRCA1 or BRCA2 testing despite a family history of breast cancer, declaring that it would be “like a sword

hanging over my head.” Yet she neglects to report the increased risk of ovarian cancer with a BRCA1 or BRCA2 mutation. Because ovarian cancer is often asymptomatic in its early, more curable stages, it’s typically not discovered until later stages. The standard recommendation for women with BRCA1 and BRCA2 mutations is prophylactic removal of the ovaries. I did just that after learning that I have a BRCA1 gene mutation. I also adhered to screening guidelines for women at high risk for breast cancer, and subsequently an MRI found my breast cancer at an early stage. I was treated and cured. My choices may not fit every woman who may carry BRCA gene alterations, but those women should be fully aware of what they’re deciding.

**Ellen Freeman Roth** // Weston, Mass.

## A Deadly Spread

*Proto*’s recent story on metastasis (“The Killing Fields,” Fall 2009) states that prostate cancer cells can live only in bone. But in fact, such cells commonly spread to lymph nodes. I am familiar with a patient who has metastatic prostate cancer in both lungs. The nodules are slowly growing (and therefore clearly content with lung tissue).

**Michael A. Linshaw** // Pediatrician, Massachusetts General Hospital

*Joan Massagué, chair of the cancer biology and genetics program at Memorial Sloan-Kettering Cancer Center in New York City, responds: Prostate cancer metastasis occurs in bone in the vast majority of cases. Metastasis to the lungs and adrenal glands occurs in a small percentage of cases. However, as the disease reaches an advanced state, metastasis tends to be more widespread; this is true in most types of cancer.*



**WHAT’S YOUR TAKE?** Write to protoeditor @mgh.harvard.edu to comment on a story—or offer suggestions for future topics.

**stat:** an abbreviation for the Latin *statim*, an adverb that signals a need—for a surgical instrument, a medical supply or, as in this magazine, a short, compelling story—to be met without delay.

JAMES GILLRAY, PRINT COLLECTION, MIRIAM AND IRA D. WALLACH DIVISION OF ART, PRINTS AND PHOTOGRAPHS, THE NEW YORK PUBLIC LIBRARY, ASTOR, LENOX, AND TILDEN FOUNDATIONS



- 06 INTERVIEW //**  
Rita Charon:  
The literary physician
- 07 BY THE NUMBERS //**  
A pungent problem
- 08 INFOGRAPHIC //**  
Paying it forward
- 09 MILESTONE //**  
A hands-on history

- 10 POLICY WATCH //**  
The cost of free drugs
- 11 THE LIST //**  
Lyrics to save lives
- 11 DEFINED //**  
Ghostbusting

**FOCUS //**

**AN AILMENT THAT USUALLY STRIKES** during ages of opulence now afflicts 5.1 million Americans. The return of gout, which is caused by uric acid crystallizing in the joints, is linked with the obesity epidemic. The overweight produce too much uric acid and don't excrete it well. Though gout has been around for millennia, the condition is still often underdiagnosed and mismanaged—more's the pity, now that the FDA has approved Uloric (febuxostat), the first new gout drug in 40 years, which lowers uric acid more effectively than previous treatments.

INTERVIEW //

**The Literary Physician**

■ BY MARY PHILLIPS-SANDY

*When physician-writer William Carlos Williams was asked how he managed his dual careers, he replied: “It’s no strain. In fact, the one nourishes the other, even if at times I’ve groaned to the contrary.” It’s a philosophy shared by Rita Charon, director of a new program in narrative medicine at the Columbia University College of Physicians and Surgeons, where students and clinicians learn to shape the fragments of medical work—a symptom, a conflict, a difficult conversation—into coherent narratives that reflect not only their points of view but also the patient’s. Charon, who trained as an internist and as a literary scholar, explains how a habit of narrative writing can change the way a medical professional sees her patients and herself.*

**Q: What is narrative medicine?**

**A:** It’s knowing what to do with stories. My group and I have developed many, many narrative practices and routines for teaching and clinical work. One is called the “parallel chart.” We give clinicians or students this instruction: Write the things about your care of a patient that do not belong in his or her chart. These parallel charts expose matters that open up in the care of an individual patient, even if they’re simply things like “I’m angry at this guy,” or “This woman makes me sad.”

**Q: How is a parallel chart different from a diary?**

**A:** It doesn’t absolve the physician from having to write down a patient’s blood pressure or glucose reading. It’s a way to remember the other dimensions of care—your own response or concerns. Narrative skills help in articulating a disagreement, help everyone tolerate the reality that there are many ways to look at something. It is a matter of enlarging the perspective, one patient at a time.



**Q: And are physicians good at it?**

**A:** Not just physicians—nurses and social workers, chaplains, physical therapists and administrators too. The writing is gorgeous, and I'm not surprised, because it's serious writing about grave matters. Even if it's done in three minutes, it's being done for a purpose. It canonizes the ordinary things we do every day.

**Q: You've said such writing shouldn't be done in a vacuum.**

**A:** Right. The more this can be discussed with colleagues, the better. Each narrative is unique; each of us sees things others don't. One person may be very aware of the setting, of where a story takes place. Another says, "Why does that matter?" The point is to widen the discourse of medicine.

**Q: Has there been research to quantify the impact of narrative medicine?**

**A:** We did a study in the pediatric oncology department at Columbia after six weeks of narrative seminars. Participants said what they did in the seminar spilled over onto the ward: Things they learned about patients' situations or about their colleagues' observations influenced their work. My next goal is to test the clinical effectiveness of these methods on how well patients can care for themselves, because narrative medicine allows a physician to relate to a patient in ways that increase the patient's understanding of her situation and can improve the ability to go along with medical recommendations. There's a sense of partnership and investment, of the physician not feeling like a stranger. If a patient feels respected, empowered,

attended to by the doctor—if a patient feels her values and opinions are going to matter—she's more likely to feel that the decisions she makes belong to her. Plus, a patient can better comprehend what she is thinking about by virtue of having a competent listener.

**Q: Were there specific authors who informed your ideas?**

**A:** From the beginning of my graduate training in English, I was consumed by Henry James. What James does better than anybody is perceive. When he describes a conversation, not only do you know what words people use, you know every nuance of feeling. Likewise with Marcel Proust, whose narrator in *À la Recherche du Temps Perdu* perceives at such a degree of fineness. Reading Proust, we find ourselves more porous to our surroundings, to our affective states, to what happens during the day.

**Q: Your fourth-year students are examining another key to narrative medicine.**

**A:** In one of several components of an intensive monthlong elective for fourth-year medical students, I teach a contemporary fiction seminar. This year I have chosen four contemporary novels: *So Long, See You Tomorrow* by William Maxwell, *The Sea* by John Banville, *Out Stealing Horses* by Per Petterson and *Kyra* by Carol Gilligan. All use associative methods of telling, braiding story with story, telling one story by virtue of telling another. The combination is an unforgettable experience in the how of telling—how some things cannot be told except aslant and how the dutiful reader has to follow his or her teller at such a pitch of imagination and alliance. It's wonderful training for doctoring. ■

BY THE NUMBERS //

## A Pungent Problem

**25** Percentage of adults worldwide affected by chronic halitosis, or bad breath, most of which is caused by oral bacteria's breaking down proteins and producing volatile sulfur compounds that coat the tongue

**615** Number of bacteria species that researchers at the Harvard School of Dental Medicine counted in the human mouth

**15** Percentage of halitosis cases that originate somewhere other than the mouth, as the result, for instance, of sinus infections, diabetes, kidney failure and metabolic disorders

**5** Highest number on the organoleptic scale (for which trained experts sniff and rate a person's breath), denoting "extremely foul odor"

**25–34** Age range during which the incidence of halitosis is greatest, according to a study, published in 2005, of patients at the Department of Conservative Dentistry in Warsaw, Poland

**6.7 billion** Dollars spent in 2007 on mouth-freshening products in the United States

**10** Number of questions on a survey created to assess a halitosis patient's psychological state; patients who complain of bad breath but have no detectable halitosis could be suffering from pseudo-halitosis (imagined halitosis) or halitophobia (an obsessive-compulsive disorder)

**10** Percentage of people who would inform a friend or family member if he or she had persistent bad breath, according to a recent poll of 1,500 patients at a dental practice in Cheshire, England ■



07

INFOGRAPHIC //

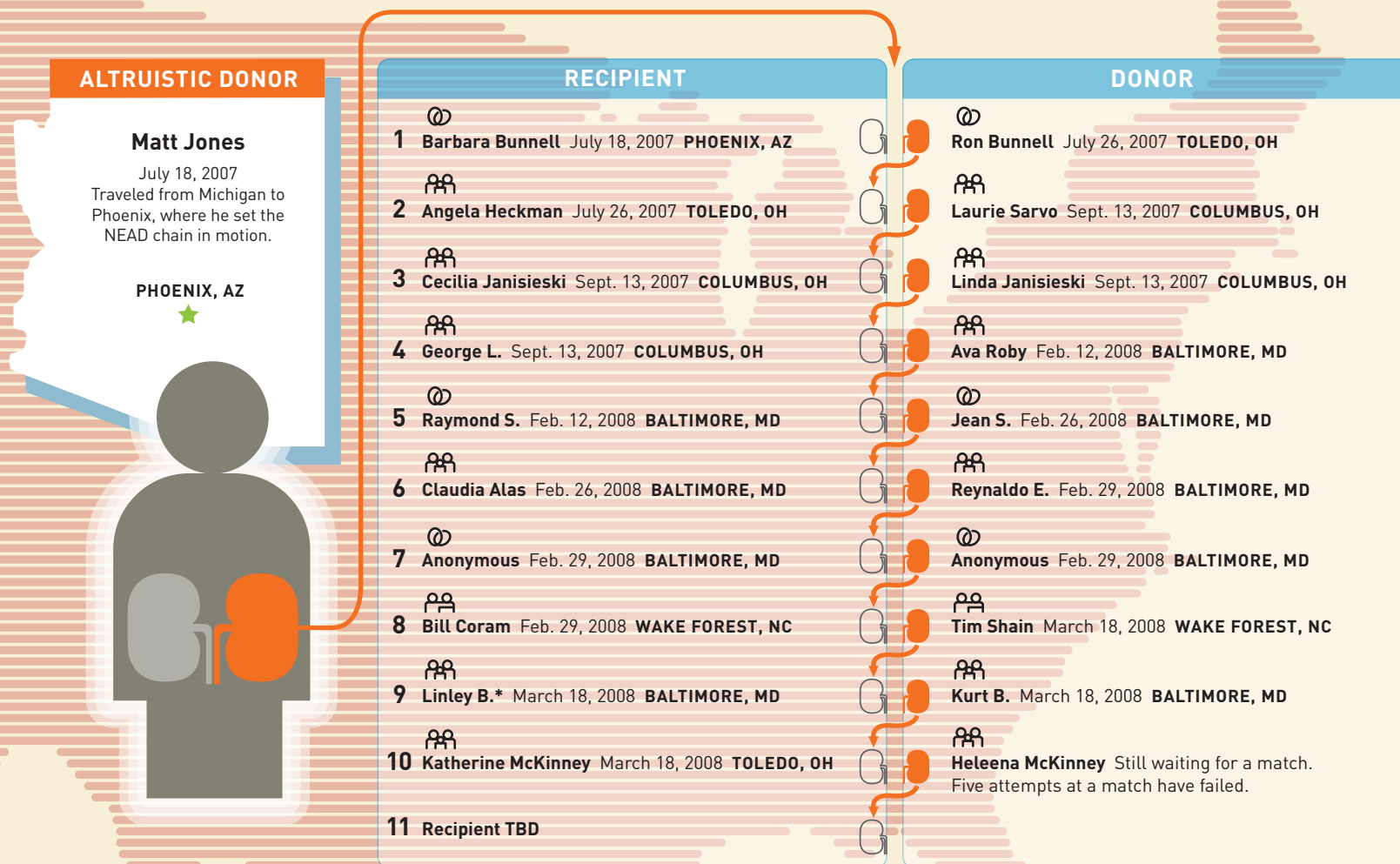
## Paying It Forward

■ BY JENNIFER BAILS // INFOGRAPHIC BY FLYING CHILLI

Across the United States, more than 83,000 patients with end-stage renal disease await a kidney transplant. Many of these people will be on the United Network for Organ Sharing waiting list for more than five years until they receive a kidney from a deceased donor; each year, several thousand die waiting. To make at least a small dent in this toll, surgeons are attempting a new transplantation strategy called a nonsimultaneous, extended, altruistic-donor (NEAD) chain—a trend that began two years ago when a 28-year-old college student and father of four from Michigan donated a kidney to a stranger, simply because he could. Here's how it works—and why not all feel it's a good idea.

### Links in the NEAD Chain

Once the Good Samaritan donates his or her kidney to a recipient, that recipient's incompatible donor (the "bridge donor") goes on to donate to someone with whom he or she is compatible, and so on—in theory, forever.



**KEY**

- Transplant recipient
- Living donor

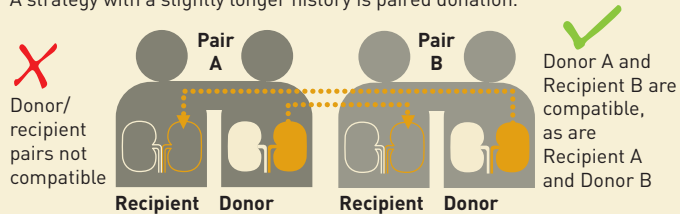
**Incompatible donor/recipient relationship**

- Family member
- Spouse
- Friend

\*Recipient has since suffered rejection of the kidney.

## A Fair Trade: Paired Donation

A strategy with a slightly longer history is paired donation.



Surgeries are typically performed simultaneously so donors can't back out after their partners receive a kidney. As of December, 709 patients in America had received kidney transplants via paired donation.

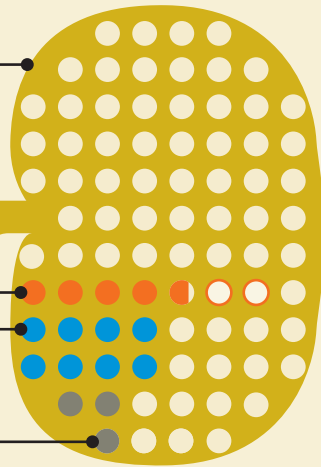
## The Grim Numbers

In 2009, some **83,000** Americans with end-stage renal disease awaited a kidney transplant

**4,725** patients received living donor kidneys.

**7,923** transplants were performed using cadaveric kidneys.

**2,987** died waiting.



- One-third of patients cannot accept a kidney from a friend or family member because of blood type or immune system incompatibilities. Patients who have no compatible donor usually end up listed for a deceased donor kidney transplant—but they can also enroll in a registry for paired donation.
- Recipients of kidneys from living donors fare better than those who receive cadaveric organs—on average, a deceased donor kidney lasts only half as long. That's because a kidney from a living donor is usually transplanted right after removal; the donor is often a close relative, so there's less likelihood of rejection, and the operations can be scheduled when donor and recipient are in the best possible health.
- An additional 2,000 to 3,000 Americans could undergo transplants each year if NEAD chains were organized through a nationwide registry, estimates University of Toledo Medical Center urologist Michael Rees. This would save roughly \$400 million each year in dialysis costs.

## The Controversy



In a NEAD chain, if for some medical or personal reason the bridge donor fails to give a kidney, the chain will be broken. But the next donor/recipient pair can still enter into a new paired donation or chain, says Rees. But some experts contend that isn't enough. "The possibility of huge disappointment and heartache calls into question the legitimacy of this strategy," says Ron Shapiro, director of the kidney, pancreas and islet transplant program at the University of Pittsburgh Medical Center. Ethicists also are concerned about whether kidneys from altruistic donors should be allocated first to patients on the deceased donor waiting list. Rees argues that NEAD chains still benefit patients without willing donors because each subsequent transplant in the chain takes a candidate off the waiting list. Others worry that NEAD chains put too much pressure on bridge donors to risk surgery.

## MILESTONE //

### A Hands-On History

Fifty years ago, a landmark paper described "closed-chest massage," soon to be known as cardiopulmonary resuscitation. CPR was the culminating discovery made by a man whose perspicacity has saved countless lives. Remarkably, the individual crucial to the development of CPR, the first closed-chest defibrillator and the very knowledge that electricity can jolt a stopped heart into beating was not a physician but an electrical engineer.

William B. Kouwenhoven was already 74 years old when he told the world about CPR in a 1960 paper published in the *Journal of the American Medical Association*, but his life work began in 1928. It was then that Consolidated Edison of New York, concerned by the alarming number of linemen deaths, asked Johns Hopkins University and other research facilities to find ways to reverse the effects of accidental electrocution. The university assembled an interdisciplinary team, headed by a New York-born, German-educated "pipe-smoking, contemplative" professor of electrical engineering known "for his creative mind," as a 1998 article in *Hopkins Medical News* described Kouwenhoven.

After studying the effects of electrical shock on rats and dogs in 1933, the group reported that although an initial shock (such as electrocution) could stop a heart, a second shock administered quickly enough could restore a heartbeat. The discovery eventually led physicians to perform surgery and place electrodes directly on a patient's heart.

Yet open-heart defibrillation could hardly be performed on utility workers in the field. So the Edison Electric Institute gave scientists a grant to develop a practical technique. In 1957 Kouwenhoven's group unveiled a closed-chest defibrillator prototype weighing 200 pounds (the team would later introduce a portable, 45-pound model).

Working to perfect the defibrillator, a graduate student on Kouwenhoven's team made a curious discovery. In 1958, G. Guy Knickerbocker noticed that even before the current was turned on, the heavy electrode paddles on a dog's chest caused the animal's blood pressure to rise. When Knickerbocker pushed the paddles in a sustained rhythm, the weight of the devices caused circulation to return. This observation led Kouwenhoven, Knickerbocker and a third member of the team, cardiac surgeon James Jude, to experiment with forceful, rhythmic pressure on the chest, which created enough blood flow to sustain vital organs until the victim could be transported to a hospital.

Following hundreds of experiments on dogs, the team applied CPR to 20 patients, reporting in *JAMA* "an overall permanent survival rate of 70%." The beauty of CPR was that medical training and equipment were not needed—medical emergency personnel as well as laypeople could easily learn and apply the technique. "Anyone, anywhere, can now initiate cardiac resuscitative procedures," the paper explained. "All that is needed are two hands." ■



## POLICY WATCH //

## The Cost of Free Drugs

■ BY MARINA KRAKOVSKY

When a physician reaches into her sample closet, the act seems helpful: Her patient can try a few doses before paying for a prescription. But in a May 2009 paper in the journal *PLoS Medicine*, two experts call the tradition of doctors dispensing samples “as anachronistic as bloodletting,” citing evidence that samples create conflicts of interest and raise prescription costs. Amid such concerns, growing numbers of physicians and hospitals are restricting or banning the use of samples.

Drug companies typically use samples to promote their new (and thus expensive) drugs, many of which offer only minor improvement over older generic or over-the-counter medications. But when a physician starts a patient on a brand-name drug that works, both individuals often resist the switch to a generic; there’s a perception among some patients that generics are less effective.

And there’s the rub, the *PLoS Medicine* paper argues:

Sticking with the brand-name drug leads to higher prescription costs. “Institutions are fooling themselves if they think allowing physicians to pass out free samples is in the institutions’ best financial interest,” says Jerome Kassirer, a professor at Tufts University School of Medicine and co-author (with Susan Chimonas of Columbia University) of the *PLoS Medicine* paper. In fact, the desire to control costs is one reason some hospitals have banned free samples.

Some physicians argue that certain patients, particularly those who require psychiatric drugs, need to test several medications for efficacy and side effects before settling on one, and that samples save them from filling entire, expensive prescriptions. Others argue that without free samples, their poorest patients wouldn’t get the medications they need. But research shows that fewer than one-third of samples go to the poor. Many are handed out to wealthier patients or to medical staff for personal use, or they’re unaccounted for. (This mismanagement is particularly troubling to pharmacists, who want samples properly prescribed and tracked.) Some indigent patients do rely on free samples, but this practice isn’t without cost: By handing out samples of a drug, physicians may get into the habit of turning to that drug even when a good alternative exists. One study found that without brand-name drug samples to hand out, physicians were three times as likely to prescribe generic medications for their uninsured patients.

“Even small gifts like samples can affect clinical judgment,” says Virginia Hood, an internist who chairs the Ethics, Professionalism and Human Rights Committee of the American College of Physicians; the ACP’s guidelines for its 130,000 members discourage accepting gifts from industry. Another strong set of recommendations was issued by the Association of American Medical Colleges, which represents accredited medical schools. As a result of its guidelines, several prominent teaching hospitals, such as Yale–New Haven Hospital and Stanford, have banned or tightly restricted accepting drug samples, among other industry gifts.

Compared with industry-sponsored junkets or “consulting fees” paid to talk up a drug’s benefits, free samples may still seem benign. But Hood thinks physicians are realizing that what seems like the right thing to do has its drawbacks. “More physicians are beginning to see the hidden costs and are changing their practices,” she says. “But change isn’t easy.” ■



Are concerns about free drug samples warranted or overblown? Share your opinion at [protoeditor@mh.harvard.edu](mailto:protoeditor@mh.harvard.edu).

## THE LIST //

### Lyrics to Save Lives

*In the Western world, public health messages reach us through numerous channels. Yet options quickly narrow for the millions around the globe who are illiterate or live in remote areas. Some health officials and community organizers are responding with something integral to all cultures: song.*

#### **“I want you to know something about wells...”**

In Cambodia, where many rivers and wells are contaminated, Resource Development International is teaching people about water safety with karaoke videos. Trucks bearing karaoke equipment arrive in villages where adults and children gather to sing along to videos addressing issues from bacterial contamination to arsenic poisoning.

#### **“This is to the youth, herdsmen and farmers...”**

When word spreads through the rural communities of northern Ghana that Sheriff Ghale, a well-known reggae artist, is putting on a free concert, thousands travel miles, many on foot, to see him. In one song, he urges listeners to help prevent Guinea worm disease by using pipe-shaped water filters. Twenty years ago, there were an estimated 180,000 cases in Ghana. Today there are fewer than 500.

#### **“Sleep under an insecticide-treated mosquito bed net...”**

In a recording of a song distributed to local radio stations,



Listen to and watch performances of selected songs and read complete lyrics at [protomag.com/songsforhealth](http://protomag.com/songsforhealth).

Malian musicians promoted a message of malaria prevention and treatment in a country where more than 800,000 people are infected annually with the disease. The lyrics stress the use of insecticide-treated nets. After the campaign ended in 2007, a survey indicated that 81% of households had nets, as opposed to 29% just a year earlier.

#### **“You see a nice face and you think you’re safe...”**

The Bashment Bus Kru rolled into rural communities and inner cities in Jamaica from 2006 to 2009, hosting informative parties for young people. The Kru, 10 youths trained in health education, incorporated reggae and dance-hall songs into skits about HIV and unplanned pregnancy. Their multicolored bus reached 45,000 young people, and as many as 3,000 took advantage of free on-site counseling and HIV testing.

#### **“Breast-feeding is power and strength...”**

Street theater has proved an important teaching tool in Ahmedabad City, in western India, with singers educating mothers about immunization, breast-feeding and newborn care. The Jeevan Daan project began in 2004 as a partnership between Counterpart International, the charity Saath and the Ahmedabad Municipal Corp. After the first five years, researchers found that immunization of children ages 12 months to 23 months rose from 48% to 77.8%. ■

## DEFINED //

**ghostbusting** [gōst 'bæst-ɪŋ] n: a term adopted in January 2009 by editors at the journal *Blood* for a movement to ban journal articles ghostwritten by uncredited contributors financed by drug companies.

In one example of ghostwriting, the Associated Press uncovered court documents revealing that GlaxoSmithKline had directed sales representatives in 2000 to recruit physician “authors” for its ghostwriting program (dubbed CASPPER), aimed at promoting the antidepressant Paxil. And pharmaceutical firm Merck was accused of paying writers to create articles from Merck manuscripts promoting the painkiller Vioxx, before it was taken off the market in 2004 because of heightened heart attack and stroke risk (Merck maintains that it has always been transparent about authorship).

Ghostbusting gained momentum in September after a study by the *Journal of the American Medical Association* found, using an anonymous questionnaire, that 7.8% of the writers of 630 articles in six leading medical journals did not credit all major contributors. Editors of some medical publications responded by calling for stronger measures to prevent ghostwriting, such as banning any contributor discovered to be lying about using ghostwriters.

Some editors at the *New England Journal of Medicine* (found by the JAMA study to have the highest rate of ghostwriting), however, have expressed skepticism, saying the JAMA researchers, whose questionnaire didn’t ask who paid uncredited sources, did not clearly define ghostwriting. ■

