



Patients, it's time to unionize:

Hospitals, HMOs, doctors and drug companies have lobbyists. But who is our advocate? Most of us have been fragmented by demographic differences and the diseases that afflict us. A union is a way to finally create one thundering voice.

By Robert Lipsyte, USA Today 8/15/07

The night before a recent CT scan, I saw *Sicko*, Michael Moore's documentary on the health care system. The next morning, instead of my usual willful numbness during regular medical procedures, **I felt a low fever of outrage at the nonchalant clerks who came in late, at the doctors who managed to screw up the semiannual order (I don't get iodine because I'm allergic) and the thousands of dollars this brief photo op would cost.** This is no horror story. I was **angry at my powerlessness and my routine subservience to the system lest it inconvenience me further or kill me:** I commiserated with the clerks who had kept me waiting — Oh, yeah, trains run late and it's really terrible having to stand in line at Starbucks; I cajoled the technicians into calling the doctor's office and having the order changed so we could proceed, and I forced myself not to think about all the people who were not adequately covered (I have Medicare and supplements) and couldn't afford my level of cancer treatment and follow-up.

And then I had an old fantasy in which I gesture toward a person sitting quietly beside me and say to the clerk, the doctor, the technician: "This is my Patients' Union representative. You don't mind if we videotape the session?" Even after almost 30 years as patient and caregiver, I feel the terrible isolation that the system has forced upon us. The doctors, nurses, technicians, the hospitals, HMOs, insurance and drug companies, all have their organizations and lobbyists, but **the largest constituency with the most at stake — patients with our lives and savings — shuffle on alone, scared, ill-informed, often naked.**

The response to *Sicko* has cranked up discussions about American health care, how it compares with that of other countries, how it can be improved, who is to blame. This is good, although I am afraid positive change will become mired in the upcoming national election: I don't believe that any one presidential candidate — Clinton, Edwards, Giuliani, Thompson, etc. — can cure us. **I think we have to take control of our own healing.**

Here's how: **A Patients Union, a combination civil rights, legal affairs and personal advocacy support system would give all our singular whimpers a mighty bellow.** It would

be a hard sell because illness is not a club that anyone wants to join. Because sick people and their caregivers have traditionally been fragmented not only by age, race, gender, class and money but also by their diseases (and often the severity of their diseases and/or the approach to treatment), bringing everyone together under one tent would take an enormous will. But, hey, if the big pharmaceutical companies can do it to keep drugs expensive, why can't we get together to force those prices down?

I first floated my Patients Union idea a decade ago, on a national book tour for *In the Country of Illness: Comfort and Advice for the Journey*. It began as tongue-depressor-in-cheek when the conversation got heavy with tales of insensitive doctors and treatments unavailable or denied. I tried to lighten the mood with a little tumor humor (doc spelled backward is "cod," not "god") and how the initials for the Patients Union, PU, signify that health care stinks. But people weren't laughing. They were asking for the non-existent union application forms. Not being an organizational type — I didn't even collect names and addresses — I never followed up with my idea. I also figured that it was such a good idea that someone else, maybe one of those Internet wunderkind types, would spread it on the cybervine. It never happened. For 10 years, the debates over health care continued and the crisis deepened.

The time has come again to talk union. I remember how, in bookstores, libraries, community centers and on call-in shows on my tour, people dealing with lupus, multiple sclerosis, Crohn's disease, diabetes, sickle cell anemia — not to mention the many types of cancer, neurological disorders and mental illnesses — discovered a community. Each of their diseases had its own laboratory and lobbyist, national society, celebrity chairman, board of famous doctors and, too often, financing from a drug company profiting from the disease. Each disease competed for government money, publicity and TV movies of the week. Meanwhile, all the lonely patients were struggling against individuals and corporations that seemed to exist merely to say, "No, we can't help you."

The Patients Union would exist to say, "Yes, we can." It could help in small yet critical ways by sending along a sidekick to be a second pair of eyes and ears (and notebook and tape recorder) during an important doctor's appointment, or an HMO or insurance company meeting. It could help in big ways by threatening picket lines, adverse publicity and consumer withdrawals when services are withheld. Perhaps most important of all, a Patients Union would give all patients a forum to remind each other that **as tax-paying citizens and customers, we have a right to demand service, to get information and to be part of the decision-making process. And that no one has a right to punish you for being sick or make you feel grateful for basic medical attention.**

As for membership requirements in the PU, all you need is a past or future medical bill.