It’s Too Hard to be Sick In America

Stories of Chronic Illness

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Foreword by
Pearl Jam’s Mike McCready

Acknowledgments

First and foremost, I must thank the patients who have allowed me into their lives so that I could learn and tell their stories, and hopefully help them out a little along the way. All names have been changed to respect patient privacy.

Second, I must thank the sponsors of this project, the Universal Healthcare Foundation of Connecticut, AstraZeneca Pharmaceuticals, and UAW Region 9a, for their generous support, as well as for the work they do to improve the lives of the chronically ill.

Third, thanks to Gloria Steinem for choosing the title in the course of a conversation we had. When Gloria says "that would be a good title for something," I take her seriously!

Thanks, also, to Nicole Netkin-Collins for her contributions to this publication.

Finally, I want to thank Mike McCready and Ashley O'Connor, not only for writing the Foreword, but for their constant, consistent, and incredibly generous support of Advocacy for Patients over the years.

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Foreword

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My wife Ashley and I met Jennifer Jaff through a mutual friend who connected us because both Jennifer and I have Crohn's disease. At the time, Jennifer was in private law practice, but was very sick and realized that her courtroom days (which made bathroom access difficult) were over. She had started doing some free work for patients with Crohn's disease and ulcerative colitis and loved it. Ashley and I encouraged her to start a nonprofit, and pledged our support. Advocacy for Patients with Chronic Illness, Inc. was born of those conversations.

For years, I watched with admiration as Jennifer got Advocacy for Patients off the ground. She is a fearless and tireless advocate whom Ashley and I have been proud to support.

But I never thought I would need Jennifer's services myself. After all, I have what is considered to be good health insurance. I'd also been on the same medication for a long time, and it had been working well for me. I'd come to assume that things would continue along without a problem.

But then I started to feel it – the churning in the lower abdomen and the urgent need to use a bathroom more than "normal" people do. I went to my doctor, who said he thought we should double the dosage of the medication I'm on for a little while to see if it would kick the disease back into remission. However, when my doctor's office called my insurer to get authorization, it was denied because the dosage my doctor wanted to try was higher than that printed on the FDA-approved label for the drug.

My wife Ashley called Jennifer, and I've never seen anybody snap into action faster. By the end of the day, Jennifer had collected my medical records along with medical journal articles about the drug – including studies that showed its use and success at higher dosages – and wrote a

detailed appeal letter to my insurance provider. All of this was faxed to my insurance company before the close of business that day.

We lost, but Jennifer didn't let that stop her. She immediately filed an appeal through the state Insurance Department, which gave the file to an independent review organization that had the authority to overturn the insurance company's decision. This time, Jennifer included more records, more scientific studies, and a letter that explained why every single other medication used to treat Crohn's disease would have been a problem for me due to side effects or prior use of the drug with no benefit. Jennifer asked that the appeal be expedited, so we would have our answer within 72 hours.

Honestly, by that point, I just assumed we were going to lose. I felt discouraged and dejected. I thought a lot about those less fortunate than I am in terms of access to resources that were dealing with this sort of thing. How is it that even when one has excellent insurance, and a doctor's prescription for a drug that will make them feel better so they can work, live, support their families that one's insurance provider can simply decline to cover the costs of that which will help you? It seemed almost unreal. More for everyone in this position less fortunate than I than for myself, we continued to pursue the answer to this question under Jennifer's guidance and expertise.

We received a call from the insurance company one week to the day from when this ordeal started, and we received great news: the independent reviewer overruled the insurance company. I got my medication. And it worked. After only a short time on the double-dosage, my Crohn's was back in remission.

I am just one of many who has benefited from Jennifer's advocacy on behalf of patients suffering from Crohn's. And the irony here is that her Crohn's is NOT in remission. Everything she does for others she does on a ton of medicine, eating only at night so she won't be sick during work hours, and even then, eating only soft foods and fluids. It's not an easy life, being

sick and running an organization on your own, raising funds to keep the work going, and showing compassion for everyone who calls or writes, regardless of whether or not she has a solution for them.

So when Jennifer told me that she was writing up stories of patients she's worked with, I wanted to help however I could. When she asked me if she could tell my story, I told her I'd do better and write the story of how her organization helped me.

Jennifer isn't one to toot her own horn. But as you read, you will find hope and information from the many cases she has resolved, and even from the ones she couldn't. The reason Jennifer is telling these stories is because she wants people who aren't chronically ill to understand what it's like to live in a broken body. She wants policy makers who talk about "chronic disease management" to understand what it's really like to live with one. She wants healthy people to begin to appreciate the obstacles faced by those who aren't. And most of all, she wants the chronically ill to know that someone "gets it."

Her words and her work are shared to serve as a resource you can hand to your friend or family member or employer or doctor or teacher and say: "Here, read this," in the hope that they will "get it," too.

I am thankful for the opportunity to add my voice to the "Jennifer-Jaff-helped-me" chorus, and I continue to hope that the health and compassion she brought my way are returned to her tenfold. On behalf of all those who have benefitted – and will benefit – from your help and your voice, Jennifer, we thank you from the bottom of our hearts.

Mike McCready
Pearl Jam guitarist

Introduction

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I am not a policy wonk; I am a patient with two very serious chronic illnesses, and through the organization I founded, Advocacy for Patients with Chronic Illness, Inc., I have worked with thousands of other patients with chronic diseases. Patients come to us for free help finding resources – from health insurance to free clinics to free medication to cash grants (which are nearly impossible to find) – and for free information and representation in disputes with health and disability insurers, Social Security, employers, and schools. So I have had a unique opportunity to live, witness, and document the obstacles facing the chronically ill.

Both as a patient and as someone who works for other patients, I try to stay informed about legislative efforts that would affect me and my clients, and I participate in discussions of public policy in an effort to ensure that the reality of what it is like to live with a chronic illness informs public policy discussions, and not some idealized or incomplete concept of the hurdles we patients face. In general, I have found that there is a lot of misunderstanding of what it's like to live with a chronic disease.

We know that, if there is to be meaningful health care reform, there must be an effort to control the cost of chronic illness, which reportedly is responsible for $0.75 of every health care dollar spent in the United States. But that means managing chronic illness, not managing patients. Indeed, patients are a low-cost resource that is under-utilized and under-appreciated.

Studies have established the value of actively involving a patient in his or her own care. "Knowledge and experience held by the patient has for too long been an untapped resource. It is something that could greatly benefit the quality of patients' care and ultimately their quality of life, but

which has been largely ignored in the past. . . ."[1] "Collaborative [c]are acknowledges the centrality of patients as primary caregivers by integrating them as key actors in the care process."[2]

As many of us recognize, patients who learn to navigate the system, practice shared decision-making with their doctors, and evaluate their care do obtain improved outcomes, and improved outcomes reduce cost.[3] "[P]atients with an array of chronic conditions who were enrolled in a comprehensive self-care management program experienced significant improvements in adherence to medical regimens . . . , health behavior change recommendations . . ., psychosocial and emotional distress caused by illness, self-reported health status, reduced occurrence of hospitalizations, and reduced costs of care."[4] Indeed, one study found that patient-centered practice improved health status and increased the efficiency of care by reducing diagnostic tests and referrals – again, resulting in lower costs.[5]

> Around 90 percent of the care a person needs to manage a chronic disease must come directly from the patient. Evidence is growing that self-management interventions, such as self-monitoring and decision making, lead not only to improvements in health outcomes and health status, but also to increased patient satisfaction and reductions in hospital and emergency room costs. [6]

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[1] R. Tattersall, "The expert patient: a new approach to chronic disease management for the twenty-first century," *Clinical Medicine* Vol. 2 No. 3, 227-229 (May/June 2002) (citation omitted).

[2] J.H. Hibbard, "Engaging Health Care Consumers to Improve the Quality of Care," *Medical Care*, 41 (1), I-61-70, at I-64 (citation omitted).

[3] *Ibid.* at I-63.

[4] *Ibid.* at I-65 (citations omitted).

[5] Stewart, Moira PhD; Judith Belle Brown, PhD; Allan Donner, PhD; Ian R. McWhinney, OC, MD; Julian Oates, MD; W. Wayne Weston, MD; John Jordan, MD. The Impact of Patient-Centered Care on Outcomes, *The Journal of Family Practice* (J Fam Pract) 2000; 49: 796-804

[6] California HealthCare Foundation, <http://www.chcf.org/topics/chronicdisease/index.cfm?subtopic=CL613>.

Still, even among the well-meaning, there is fear that educated, complex, chronically ill patients already take too much time, ask too many questions, and make too many demands, and that educating them and building a system around the premise that patients are equal partners in managing their own health care will only increase the burden on providers.

Many policymakers err in assuming that patients want more health care than they need, so just managing the demand side of the equation will lower costs. In my experience, nothing could be further from the truth. Indeed, I would do just about anything to have a year in which the only doctor I see is my brother! I am constantly trying to wean myself off of medications, avoid doctor appointments, labs, and other diagnostics that aren't really necessary, and have a life apart from my illnesses. But I am on drugs that suppress my immune system and that can adversely affect liver function, so I must have blood work done every two months or so, and then I must touch base with a doctor to interpret the results. And there are medications I take without which I would be unable to work, and would, thus, become a greater drain on society by going on Social Security disability and either Medicare or Medicaid. In my experience, most patients feel precisely the same way.

The truth is that patients hate being sick, and want to operate as autonomously as possible. Their goal is precisely the same as that of most payers, i.e., reducing interaction with the healthcare system, thereby reducing cost. Interacting with the healthcare system is stressful and often painful, demeaning, and unsatisfying. What is needed is a patient population that has the capacity and tools to develop judgment over time so they can make better decisions about when they need medical intervention and when they can manage on their own. Although patients want *enough* care to allow them some quality of life, they do not want more than they need.

It follows, then, that most chronically ill patients want to manage their own care rather than relying on doctors and other providers. Most patients want to understand, and are capable of understanding, the system. Our current system, in which patients are subjects rather than participants, can be disempowering and condescending, and it wastes the precious resources that patients bring to bear. With a modest investment in patient education and training, patients can be in a position to become more autonomous, thereby reducing the number of interventions by healthcare personnel. Teach patients to participate in the system and they will work to manage their own disease at no cost to the system whatsoever.

Patients who are culturally and linguistically diverse from their healthcare providers are particularly needful of empowerment. Too often, Spanish-speaking patients are ignored because they cannot express their preferences, knowledge, and needs in a way their doctor understands. Similarly, insensitivity to cultural norms and preferences is an obstacle to patient participation, which adversely affects patient compliance, and, thus, results in worse health outcomes and greater costs. This does not happen because patients do not want to participate in their own care; it happens because the system as it currently exists does not facilitate such participation.

The cost, both in time and money, of training patients is minimal when compared with the saving that would accrue. First, all or even most of the training need not be performed by doctors. There is a critical role in the system for patient navigators. Whether they are social workers or lawyers or just trained advocates, the cost of patient navigation is extremely low. We work with over 1,000 patients per year at a cost of about $150,000. Thus, for an average cost of about $150 per patient *or less* if patient education is done in classes rather than on an individual basis, patients can be trained and assisted to navigate the system on their own, seeking support from

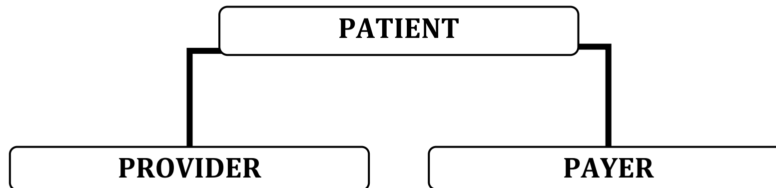
health care providers only when necessary. The use of cost-efficient patient navigators to train and assist patients would greatly reduce the burden on doctors and the cost to the entire system.

The truth is that the system cannot meet the goal of maximizing health outcomes without including patients as full participants in the healthcare system. We cannot improve health outcomes without patient compliance with doctor's orders, and patients will be more compliant if they understand what is happening to them and why their compliance is necessary. Without patient education, we will not have patient participation, and without patient participation, we will fail to maximize compliance with doctors' orders and, thus, we will not see resulting improvements in health outcomes and, in turn, cost reduction. Any attempt at reducing the demands of the chronically ill on the healthcare system will fail to reach its potential if patients are not full participants in the system.

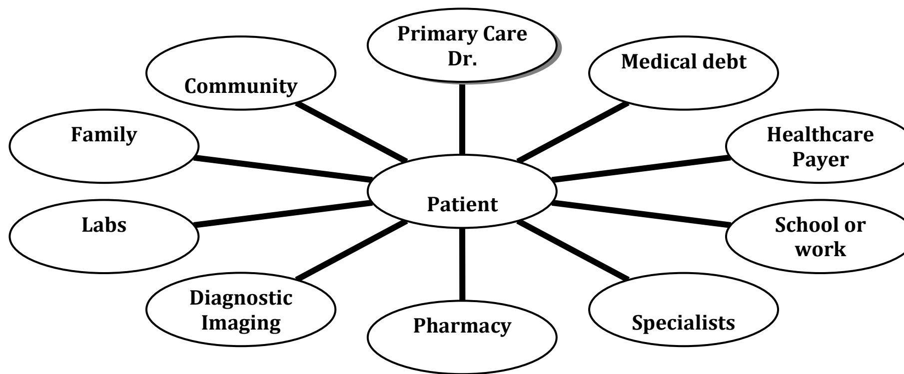
Once patients become full participants in their own care, the system will become more cost effective and efficient. For example, recently, I had a staph infection in a surgical incision. So as to manage my wound care without lengthy, time consuming, and costly doctor visits, I took a digital photograph of the wound every morning and emailed it to my surgeon so they he could monitor my progress. This allowed my surgeon to monitor my healing on a daily basis in about two minutes per day at nearly no cost at all.

But if we really are to curb the costs of caring for the chronically ill, we must have a better understanding of the obstacles they must overcome on a daily basis. For patients with complex chronic illnesses, the healthcare "system" goes way beyond the doctor's office. The chronically ill face hurdles at work and school. There are children who require monitoring and medication administration at school. There are children who require accommodations in school – an "anytime bathroom pass" for a child with inflammatory bowel disease; home instruction during a lengthy illness.

Chronically ill students and employees face discipline due to illness-related absences or limitations. For patients, the healthcare system does not look like this:



Instead, at what still is a very basic level, reality for a chronically ill patient looks more like this:



All of these elements must be managed by the patient – and under our current system, much of this management must be done by patients *without education, training, or support*. Yet, all of these elements affect a patient's ability to manage her illness.

For example, if a patient loses his job, he may lose his health insurance if COBRA is unaffordable. Adult children may lose health insurance if they are unable to stay in school full-time, and the ability to complete school will affect future employment and, thus, the ability to obtain

group health insurance.[7] The need for accommodations that allow people to remain employed or in school has a direct impact on healthcare access and, thus, health outcomes. When you have a chronic illness, work, school, financial issues, social issues – every aspect of your life – bear on your access to healthcare and, thus, the quality of health outcomes and, in turn, the cost of your care. Any plan for health care reform that purports to address chronic disease management must recognize the scope and complexity of issues facing the chronically ill, all of which affect healthcare access, and, thus health outcomes.

What steps must we take for patient-centered chronic disease management – whether we call it "medical home" or use some other model – to function efficiently and effectively?

1. Any plan for healthcare reform must include a mechanism by which patients are trained to help manage their own care. Patients must be seen as a resource, and must be encouraged to be full participants in their own care.

2. Any plan for healthcare reform must include a means to address the full range of issues that affect healthcare for the chronically ill, including ways in which to meet their needs not only at home and in the doctor's office, but also at school, work, and in public places. The full extent to which chronic illness invades the life of the patient must be recognized and built into any system of reform.

3. In order to maximize cost-effectiveness and efficiency by fully utilizing patients as participants in the management of their illness, any plan for healthcare reform should implement a system of patient navigators – nurses, lawyers, social workers, trained advocates – who can educate and assist patients to navigate the system as a whole, beyond the medical office.

[7] Although, for fully funded plans, some state laws, including Connecticut's, now require coverage under a parents' plan up to age 26, this is not the case for members of self-funded plans, nor is this the case in the majority of states.

We should not rely on physicians to do this work.

4. Patient navigators should be selected and trained to recognize linguistic and cultural diversity among patients.

5. Any plan for healthcare reform should implement uniform standards for medical record keeping, and patients must have access to their records. Every office visit should include a weight and a list of current medications. The patient's complaints should be well recorded. As we move to electronic records, illegibility will be eradicated, and patients who wish to self-advocate should have an easier time collecting their records, and doctors should stop charging for copying records when it becomes no more complicated or time consuming than simply pushing the "print" button on a computer.

In sum, to accomplish the goal of creating cost-effective, efficient, successful chronic disease management programs, we must appreciate and address the complexity and scope of issues that affect healthcare access for the chronically ill. If we view the health care system through the lens of the patient, we can see that health care means not only medical care in the narrow sense, but instead includes all of the ways in which a patient's health affects her life, as well as the ways her life affects her health. Seen through this lens, a successful disease management program will engage, educate, and support the patient in learning to participate in his or her care so as to maximize compliance and, ultimately, health outcomes.

The Universal Health Care Foundation of Connecticut's *SustiNet* plan comes as close to meeting these goals as anything I've seen.[8] As I said in my testimony before the Public Health Committee of the Connecticut General Assembly, *SustiNet* would manage chronic illness in an effective, patient-centered way, by creating a patient advisory committee that will help govern medical homes that will assist the chronically ill to monitor and manage

[8] Raised Bill No. 6600 (2009).

their conditions; promote exercise, nutrition, tobacco cessation, and sleep; implement best practices to ensure compliance with medical directives; and provide for cultural competency and sensitivity. The medical home will be available 24 hours a day, seven days a week. It will be the patient's point of entry into the health care system, where care will be coordinated, managed, and monitored. *SustiNet* recognizes the value of patient participation by establishing a framework in which patients partner with their health care providers to manage their care. This not only will empower patients, but it will increase their compliance with physicians' orders, which will improve health outcomes, which, in turn, will reduce health care costs.

Second, *SustiNet* recognizes the nature of chronic illness by defining "care coordination" to include strategies to address stresses that arise in the workplace, home, school and the community, with referrals to employee assistance programs and other nonmedical services such as housing and nutrition programs, domestic violence resources, and other supports. The patient advisory board would have the ability to develop other community-based resources, like ours, which help people to navigate the insurance and legal systems through low-cost patient education and limited interventions. And cultural competence and sensitivity are ensured by this Bill.

These aspects of *SustiNet* make it, in our view, superior to other proposals. In short, *SustiNet* "gets" chronic illness and the many challenges facing the chronically ill.

The rest of this book is comprised of stories that illustrate these points. I leave it to others to craft statements of policy; my goal here is to help you understand what our lives are like so that you can measure public policy proposals against our reality. My premise is simple: You can't fix what you don't understand. So read on and get a sense of what it likes to live in a body that doesn't work right. If I'm a reasonably good story-teller, I will not need to say any more.

Me

I suppose if I'm going to tell patients' stories of their experiences with the healthcare system, I have to start with my own. I was about 19 years old when I was diagnosed with Crohn's disease. I'd been pretty sick for awhile – I lost about 80 pounds in three months. I couldn't keep a glass of water in me. The doctors mistook Crohn's in my upper gastrointestinal track for an ulcer, and due at least in part to this error, I recall driving to college each day in traffic and having to pull off the road, vomit, and then make my way to school. Back then, there were few medication alternatives; my diagnosis at age 19 marked the commencement of 12 years of continuous steroid therapy that has left its mark on me and will forever.

The doctors thought the stress of law school was a bad idea, which made me that much more committed to attend. I had a lovely gastroenterologist in Washington, DC, where I went to law school. He admitted me to the hospital during breaks from law school to feed me intravenously and let my bowels rest. That, steroids (prednisone) that I took every day, and a trusty bottle of Mylanta that I carried with me everywhere, got me through law school.

During my first year out of law school, I taught legal writing at Vermont Law School, which is about 40 minutes away from Dartmouth. I assumed that doctors at Dartmouth's hospital would, at the very least, be adequate.[9] After several months and a lot of medication, they decided I needed surgery to remove my cecum, a piece of my intestine. It was the worst decision I have ever made.

First, a nurse decided that I did not need pain medication after the first night, so she took it upon herself to change me from a morphine drip to

[9] Dartmouth now has an Inflammatory Bowel Disease Center that is quite excellent.

Tylenol. I had an incision that went from above my navel down to my pubic area, and one day after surgery, she gave me Tylenol. I demanded to see a doctor. It was hours and hours of agony before a resident came and restored my pain meds. I still remember that pain.

Then, when I was ready to be unhooked from my many tethers, a resident tugged the tube out of my nose despite the fact that it was stuck to my nose with dried blood. He pulled off a small piece of my nose with the tube. Just to make sure I'd never forget the experience.

So that was surgery number one in 1984.

I was feeling no better after all that. I was still on steroids – for about seven years, now – and was sick as a dog. My parents gave some money to the Crohn's & Colitis Foundation of America (which had a different name then), and the son of one of their founders, the remarkable and adorable Michael Modell, took me by the hand (literally) to see his doctor in New York. Dr. Daniel Present pronounced that surgery had been a terrible mistake, and started me on Imuran, an immunomodulator that he was championing at the time – and which now has become the standard of care.

My next job was at the University of Miami School of Law. The doctor in Miami, recommended by Dr. Present, was excellent. He tried to wean me off the prednisone, faithfully testing my blood for liver function abnormalities due to the Imuran regularly. Nothing helped. I was still going to the bathroom 10 times a day, at least.

Then I decided to take things into my own hands and live and eat healthier. I started swimming. I lost a total of 120 pounds. I was tan and fit and I felt good. I finally got off the steroids. All was right with the world.

Things continued like that for a long time. I clerked for a federal judge, then moved to Connecticut and did some teaching and some research and brief-writing. My health was stable.

Until I got an intestinal blockage. That meant immediate surgery. Surgery number two was in 1993. This time, the surgeon took out a portion of my terminal ileum, which is where the large intestine and small intestine meet. This is the most common location of Crohn's disease. It's also the part of your intestine that absorbs B-12 and bile salts, which means surgical removal requires substitution with supplements – forever.

Several more blockages followed over the years. I learned to tough them out when I could, and doctors got better at using a naso-gastric tube (down your nose into your stomach) to relieve pressure from the blockage and avoid surgery. But surgery number three came along in 2001. Another blockage. No choice.

The surgeon begged me to try a dose of steroids while I was still in the hospital, before resorting to surgery. I reminded him of my previous reactions to them – that I not only gain weight, stop sleeping, and become manic, but I become full-blown psychotic. Still, he begged me to try just one dose. Sure enough, I went absolutely nuts. A male nurse gave me only half of the medicine in a syringe, and when he blew me off when I asked why, I squirted the rest of the syringe in his direction. He said I got some of it in his eye, although it was flushed and he was fine. I was then tackled by 4 large people and made to stay in my bed. I don't think they actually used restraints; I don't remember. But I do remember being so out-of-control that I called several people and asked them to come get me despite the fact that it was the middle of the night. The police even came. Dammit, I told the doctor this would happen. Of course, the next day, the surgeon apologized for not taking my word for it and promised I would never have to prove that I get steroid psychosis again. Yeah, right. To this day, the doctors say "you don't want to try steroids," rather than "you can't have steroids," as if it's a choice I am making. The truth is that if I ever had to be on steroids, I would have to be sedated and restrained. And yeah, I won't do that voluntarily.

But then I got really sick, dying sick. First, I got c-difficile, a bacterial infection that's very common in the intestines. I became fecally incontinent. That persisted for eleven months. If you have not had the experience of being incontinent in your sleep, you don't know hell.

I finally changed doctors and we got the incontinence under control, but I was very sick. I was going to the bathroom 20 or 30 times every day. There was nothing "safe" that I could eat. I was on every medicine anybody knew of for Crohn's and then some. Nothing worked. Tests showed severe, active disease in my stomach, duodenum, small intestine, and large intestine. The sicker I got, the less my doctor wanted anything to do with me. He simply couldn't say "I don't know." I kept pushing him, begging him to do something. He wrote me a letter saying that I should learn to keep emotion out of my relationships with doctors. I was dying and he didn't want me to be emotional.

Finally, I went for a consult to an expert in Boston who gave us a laundry list of things to do, starting with another round of scopes – a colonoscopy and upper endoscopy, or what the doctors call a "double dip." My doctor's office called and said they had an opening for scopes the next day. But I had a court deadline and I needed a little notice. That's when my doctor pretty much quit on me. He tried to make me wait for months for the scopes; his feeling was that if I prioritized a court deadline above the scopes, then any subsequent waiting was my fault. Finally, I got the scopes scheduled, and they showed active disease from stem to stern again. But by then, my doctor wanted nothing to do with me. If I could work at all, he felt, I wasn't all that sick. He ignored the fact that I had to work or I'd have lost everything – my job, my house – everything I had worked for. He just shut down on me.

It was around this time that my legs started to swell. My primary care physician did blood work, tried diuretics, but he had no idea what was

causing this "pitting edema." The swelling got worse and began creeping upwards until my face became swollen and I got really scared. My primary care physician had me admitted to the hospital for kidney and liver consults. Both geniuses said I was fine except for my Crohn's disease. The hospital was disgustingly filthy. I had a PICC line (a high-test IV line) inserted so that I could be sent home with IV fluids; I carried a little pump and supplies in a backpack. But nothing got better; I just continued to blow up. The day the doctor told me how to wrap my legs if the skin began to split because it was stretched too far, I decided I needed to take things into my own hands.

At around this same time, I woke up to find the PICC line hanging half-way out of my arm. I called the home health care company that was supposed to be monitoring it and they told me to call my doctor. I called my doctor, but even though he was on call that morning, he refused to speak to me and told his answering service to tell me to call the home health care company. I told them I already did. So the service called the doctor again and he grudgingly called ahead to Hartford Hospital Interventional Radiology to tell them to expect me. When I arrived, a physician's assistant simply shoved the PICC line back into my arm without any preparation or sterilization. Had I not gotten a pus-filled staph infection in my arm within 24 hours, it would have been a miracle. No miracle here; my arm blew up, got red with green pus on the edges, and the PICC line had to come out.

Afraid of my skin splitting, and abandoned by the doctor who had been treating me, I called a friend at the Crohn's & Colitis Foundation of America and asked for the best doctor in driving distance. He directed me to Dr. Ellen Scherl in Manhattan. She spent 1.5 hours just taking my history and then she told me that my kidneys were shutting down. I was seriously deficient in albumin, protein, calcium and vitamin D. For fluid to be directed into the blood cells rather than the lymph, the body needs albumin. Without albumin, the fluid goes into the lymph and you get swollen. Diuretics are the

wrong thing to do – they drive even more fluid out of the blood cells, which is why my blood pressure tanked a few times.

Dr. Scherl immediately sent me to an endocrinologist, and then a nephrologist, both of whom explained that the inside of my intestines were like third degree burns, through which all nutrients seep out. They said that, like a burn victim, because I was not absorbing essential nutrients, I was seriously deficient and my kidneys were starting to shut down and I was dying. One week, I'm in Connecticut being told it's no big deal, and the next week I'm in New York being told I'm dying. Based on how I felt – I could not even sit up in a chair in a doctor's office waiting room and had to lie down on the floor – I tended to believe the more pessimistic viewpoint.

It's good that I did, because loading me up with albumin, protein, calcium and vitamin D solved the problem. I peed out 23 pounds of fluid in two days and no longer was blown up.

Dr. Scherl then put me on pretty much every medication that had any hope of resolving my Crohn's disease. I went for intravenous infusions of Remicade every four weeks at an infusion center where most patients were getting chemotherapy. One day, something went wrong. My blood pressure tanked again. It was really scary. They put me in a wheelchair and ran me (literally) to the emergency room. I'm not at all sure what they did at that point, but I know that incident was followed by a liver biopsy that showed that the Remicade had destroyed half my liver. My immune system had started attacking it and did pretty significant damage. No more meds in that category for me – ever.

By that time, I was taking every prescription medication known to help with Crohn's disease and then some – a total of 17 different medications. As my condition began to improve, it became clear that I had scar tissue – adhesions – that were causing unbearable pain. Another surgery – five hours long – took place in November 2003, followed by two

hernia repairs in January 2004 and March 2005, so this entire siege had lasted almost four years. That was four years of my life gone, all because the doctors in Connecticut – including the most senior gastroenterologist at Hartford Hospital – weren't prepared to say that things had gotten out of hand and they didn't know what to do. Had I not gotten scared enough to go to New York and see the best of the best, I would be dead.

And the story never ends. About two years ago, I started getting nausea and vomiting, mostly around food. I told my doctor I had mild gastroparesis. He said "fine, what would we do if that were the case?" I said "Reglan," so we tried Reglan and it worked. But one of my other doctors is afraid of Reglan because it can cause irreversible tardive dyskenesia or facial ticks. So we tried Erythromycin and I vomited. We got the non-FDA approved Domperidone from Canada and I vomited. Reglan it is. And Protonix, a proton pump inhibitor that helps control nausea and vomiting, too.

At roughly the same time, I again developed acute abdominal pain that was very focused and frequently caused me to double over. It hurt so badly that it woke me from sleep. My primary care physician ordered a CT scan, which the radiologist thought was normal. For almost a year, I lived with that excruciating pain, until my symptoms worsened again and I lost 40 pounds in about a month. Finally, I had the green light to go see the surgeon. I brought him the CT scan on CD-ROM, he inserted it into the disk drive, and in moments he was able to show me the source of my pain: a piece of intestine was stuck to a piece of hernia mesh. Because we thought it was the cause my inability to eat and my weight loss, the surgeon scheduled surgery immediately.

Surgery (and yet another staph infection in the incision) came and went, as did the pain, but the nausea, vomiting, and inability to eat were unresolved. So we decided to do some more diagnostics. Ultimately, I had a

gastric emptying study, which measures the amount of time it takes for the stomach to break food down and pass it on to the rest of the digestive tract. I sure do have gastroparesis; I had zero gastric emptying in 90 minutes! The food just sits in my stomach. So I'm not hungry, but I am nauseated. I go to the bathroom 10 times a day when my Crohn's supposedly is in remission. If I try to decrease the Protonix or Reglan, I start vomiting immediately. Indeed, I had my first serious vomiting attack that lasted two days, until I took Phenergen suppositories, which made me loopy, but at least the vomiting stopped.

For now. This is how I live. I ingest liquids and soft foods only. I take 15 or so prescription medications plus vitamins and probiotics. I live in fear of the other shoe dropping. Once I cannot control the vomiting and keep even liquids down, I will have a choice between a feeding tube and dying – and I am going to decline a feeding tube. So it's only a question of time. In the meantime, although I try hard to eat enough, I'm exhausted constantly.

The cost of all of this is astounding because of the co-pays I have to pay every time I go out-of-network. Every out-of-network colonoscopy costs at least $1,000 more than what my insurance pays for it, but nobody other than Dr. Scherl has been able to get a scope through all the twists and turns and scar tissue that mar my intestines. My medication copays are over $100 a month every single month. And my monthly health insurance premium is $1,000. In short, my healthcare costs at least $15,000 per year *in addition to what my insurance covers* every single year, even when I am relatively stable. When I have a surgery or other procedures, the cost increases.

Recently, I got a letter in the mail from my insurance company. They have decided to exclude Protonix – which I need in order to avoid vomiting – from their preferred drug list or formulary. I panicked. I called a friend in the insurer's legal department and begged, and he got my "appeal" expedited. They needed records, so I got my doctor's office to fax what they

needed. I called the Attorney General's Office and had them lined up to pounce if my request for an exception didn't go through. Three days before I would have run out of Protonix, the request for an exception was granted – for a year. So I only have to panic once every twelve months.

That pretty much brings my story current, although there are plenty of details I'm leaving out. Everything is a fight. If I'm not fighting about Protonix, I am fighting to get my insurer to pay the majority of what my New York doctor bills. I take 15 different prescription medications, and just getting those filled monthly, with doctors calling in refills on a timely basis, is overwhelming. When I travel, I can't eat – period. I work very full time, but most of the time, it's prohibitively difficult to leave the house – and, thus, the bathroom – for long periods of time.

My current philosophy is that I have spent the last 33 years doing everything the health care establishment has told me to do, and it has left me with diarrhea, nausea, vomiting, 15 prescription medications, 8 surgeries, over $15,000 per year in expenses – and far, far more in the bad years – and not a lot of trust in health care professionals, along with an intense hatred for nameless, faceless people at insurance companies who make decisions about what to cover and how much to pay without ever even wondering about the consequences their actions will have for the patient.

So now I spend my time representing other patients in an effort to put my nightmare to some good use.

Amy

Amy is the mother of five children. The youngest, Heath, has several severe chronic illnesses, including mastocytosis, urticaria pigmentosa, and solar urticaria – an intolerance to natural sunlight. Although the family has health insurance, Heath needs medications that are prepared by a special "compounding pharmacy." He has constant diarrhea and goes through many diaper changes every day. But most of all, he needs to live in a house in which he is protected from the sun, and he needs to be kept in a cool environment, so the air conditioning bills are extraordinary.

Amy is resourceful and relentless. She *will* make sure her child has what he needs. So she works at night so that she can be with Heath during the day. She has set up a website for Heath, and has organized one fundraiser after another. Her goal has been to install special tinted windows throughout the house so that Heath is safe at home, and to add an indoor playroom where other kids can come and play with Heath so he is able to socialize and avoid isolation.

We called or wrote to every window manufacturer in the United States. Amy finally got some help from Home Depot, and a local builder poured a foundation for Heath's playroom. She also organized a large, upscale fundraiser that brought in a little money, and some people in her town helped out. At one point, when the mortgage payment was overdue, I asked friends and family to write checks and I broke one of my cardinal rules and wrote a small check myself, too. We also wrote to *Extreme Makeover: Home Edition* asking if they would help. We gathered letters of support from the Attorney General and other elected officials. Amy tapped into the Soldier, Sailor and Marine Fund to help with the mortgage. In short, we did everything we could think of to get Heath's house outfitted to meet his needs.

The mortgagor is one of the very aggressive large mortgage companies. When Amy did not have a full payment, they refused to accept partial payments. Over and over, we begged them to refinance, with the help of the Veteran's Administration, which was in the picture because Amy's husband is a veteran. Once improvements to the house were begun, the thought of losing the house became intolerable. Amy worked nights, begged, borrowed, and begged some more for any help from anybody. But there were no other resources.

We tried to tap into government-funded benefits for Heath, especially to cover his health care. The Department of Social Services said that he is ineligible for Medicaid due to the household income, despite his extraordinary needs. He is on the waiting list for a special Medicaid coverage group for children with profound illnesses. I can't begin to count the number of state employees I have spoken to about Heath. Nothing helped.

And then Amy's husband decided he'd had enough and walked out, leaving Amy with five children and no money. Month after month, Amy cobbled together money to pay at least some of the mortgage, and came close to losing the house several times. The husband, Rob, refuses to pay child support, and the State will not pursue collection until the divorce is final. The divorce isn't final because Rob wants custody of the children, including Heath, and he wants the entire family out of the house so the house can be sold and he can pocket a profit.

Heath's house. Where the foundation for his playroom has been poured. Where supplies have been donated. Where Amy fought so hard to keep Heath safe.

I have known Amy for almost three years. Never once has Rob called me for help, or even answered the phone when I've called. Indeed, Rob has been so disengaged from his family's struggles that, at one point, the person

at the Department of Veterans' Affairs who was trying to help with the mortgagor asked me if I believed Rob really exists!

And now he wants custody of his children, including Heath.

Amy is, of course, pretty hysterical. She is exhausted from years of sleep deprivation from caring for Heath during the day and working as much as possible as night. She can't imagine losing the house after spending literally years trying to make it a haven for Heath. She is broke; while Rob pockets the $6,000 per month of income he receives each month while he lives with his parents, Amy struggles to come up with money to buy Heath's diapers and medications.

There is no parent more dedicated to her child's well-being than Amy. She has entirely neglected herself – and probably her marriage – all out of a determination to make a safe haven for her very sick little boy. The thought of Amy losing the house is painful to me; I can't imagine how unthinkable it is for Amy.

But Rob did an end-run around Amy and told the bank to close out the mortgage and not accept any further payments from Amy. He could do this because the mortgage is in his name only, although both Rob and Amy's names are on the deed to the house. The home is in foreclosure. By the time you read this, it most likely will be gone. And Amy's dream of building a safe place where Heath can live and play and thrive will be gone, as well.

As soon as the house went into foreclosure, *Extreme Makeover* called. They were ready to build Heath's playroom. But they were too late.

I don't know how Rob lives with himself. Indeed, I don't know how our society – from the bank to the VA to the State to all the politicians we have contacted – can allow this to happen. How could the State refuse to enforce a child support order until a divorce is finalized? How could the State refuse to help Amy with Heath's health care, or with foreclosure assistance?

And how is Amy supposed to battle all of this with five children, no money, a profoundly sick little boy, no health care for him, no legal representation (I know nothing about family law) – nothing?

Carol

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Carol worked for a health care company. She took leave under the Family and Medical Leave Act (FMLA) as a result of inflammatory bowel disease. She had surgery, so her period of disability extended beyond the twelve weeks allotted under the FMLA. Her employer sent her a letter telling her that she could go on short-term disability, but that, since she was exceeding her FMLA leave, her position could not be held open for her, although the company would make every effort to find a position for her when she was able to return.

Carol notified her manager at the end of January that she expected to return to work when her short-term disability ended in mid-February with some restrictions. Her plan was to go back to work on a reduced schedule and ease back into full-time work. At the time she called her manager, there was a job open for her, but her manager said he could not hold the position open for her. She was told, again, that when she was ready, the company would help her to find an alternative position. She found out later that a temp was hired to fill the position that was open at the time she made inquiry.

However, when the time came for Carol to return to work, there was no open position, and the company told Carol to go on long-term disability. There was no explanation for why a temporary employee was given her job, or why that person couldn't have remained a temporary employee until Carol was able to return to work. Other employees had been allowed to return from medical leaves gradually, starting as part-time and working up to full-time. However, Carol was not offered this option. She went on long-term disability because it sounded like the only option that would continue to bring in some income, even if it amounted to only 65% of her regular salary.

I wrote the company asking that Carol be reinstated. In the alternative, I suggested a monetary settlement. I got a very polite call from a young lawyer who works for Carol's employer saying he would investigate and get back to me, which he did. Our second conversation was nowhere near as pleasant as our first; the employer's attorney felt a need to try to discredit every fact on which I had relied in my letter, although when all was said and done, the stories were pretty close to identical, at least on the points that really mattered. But the bottom line was that Carol was not going to get her job back. By going on long-term disability, Carol gave her employer the ammunition it needed: Either Carol lied in her application for long-term disability, or she was lying about her ability to return to work. A serious bind since lying on an insurance application is criminal, and the inability to perform all of the "essential functions" of one's job – including attendance – is an entirely legal basis for termination of employment despite one's disability as long as FMLA time has been exhausted.

After much verbal sparring, the attorney asked me what we would want as a monetary settlement. In general, the guideline I use is one week's severance for each year the employee has worked for the employer. So I asked for ten weeks' pay – and got it.

In the end, Carol is still out of a job. She will go on unemployment after her long-term disability expires in a couple of weeks, and she will look for another job, still unable to answer the question why she left her last employer. But there's no question that ten weeks' severance is better than nothing, and without my help, nothing most likely is what Carol would have gotten.

Ann, Kendra and Leslie

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Coordination of benefits sounds like a boring topic of cocktail party conversation, but the coordination of benefits cases I've had have been among the most difficult and intellectually challenging cases I have handled.

Ann was insured by a UnitedHealthcare subsidiary. She was on Social Security disability. Her insurance policy included a clause that said, essentially, that Medicare is primary, and if you fail or refuse to elect the optional part of Medicare (Part B), the insurer would treat you as if you had elected it, and would only pay the twenty-percent copay that would have been billed to them as secondary. However, Ann didn't realize this. Her insurer contacted her, she immediately enrolled in Medicare, and we were able to convince the insurer not to go back in recouping payments any further than Medicare would go in accepting claims. It was a nightmare of paperwork; I wrote to more than 20 medical providers – doctors, radiologists, labs, hospitals – all of whom had to refund the commercial insurer and re-bill Medicare. Because of the time frames involved, though, the end result was that everything was taken care of.

Kendra is far more complex. She was employed by a very large company that, for reasons I don't understand but am glad about, has kept her on the rolls as an active employee despite the fact that she hasn't worked in years and isn't expected to work again. She's also enrolled as a dependent in her husband's health insurance plan AND she's Medicare eligible. Her primary insurer decided, about a year or so ago, to assert that it is not really primary, and started recouping funds from her medical providers. I got involved, got both of the policies, researched Medicare, and established that, if she was still an active employee at her employer, then that insurance is primary, her husband's insurance is secondary, and Medicare is tertiary. I

wrote to both her plan and her husband's plan and they confirmed this order of coverage.

The head-ache of straightening all this out still is ongoing, though, because her insurer recouped payments from providers, and then providers had to re-file claims once we proved that her insurer was primary. A year or so later, and we are still working on this one; recently, some unpaid claims popped up, and we're working on getting them paid now. This particular patient is quite ill and had a stem cell transplant, so you can imagine the number of insurance claims that were filed. We keep trying to get the two insurance companies to work it out between them, but we can't get them to leave us out of the loop. So we keep killing trees with all the paperwork; just when we think we're finished, something else pops up.

But Leslie is in a very different place. She was disabled and on Medicare when she got married. At that time, she was covered under her husband's health insurance plan, so she disenrolled in Medicare Part B thinking she had no need for both. When her husband was laid off, they paid the COBRA premium to continue on his health insurance. However, as they approached the end of their COBRA coverage – so about one and one-half year's worth of medical bills later – the insurance company decided that Medicare is primary, and they took back all of the money they have paid to health care providers on her behalf. She immediately enrolled in Medicare, but could not enroll retroactively to the date when her insurer says she should have. So if her insurer is correct that Medicare became primary that long ago, Leslie is on the hook for all of it. She has multiple sclerosis and her health care is extremely expensive.

Here's the rule with Medicare. If you're in a large group plan (more than 100 employees), you are under age 65, and you or your spouse is an active employee, your group insurance is primary and Medicare is secondary. If you are age 65 or older and the employer has 20 or more

employees, and either you or your spouse is an active employee, the group plan is primary and Medicare is secondary. If you are not an active employee – for example, if your spouse is laid off as in Leslie's case – then Medicare becomes primary.

Many insurance policies contain a provision that states that, if you are eligible for Medicare and you don't take it, the insurer can treat you as if you did, so they will only pay as secondary, and only the 20 percent copay that they would pay if you were enrolled in Medicare.

So in Ann's case, Medicare was primary because she was in a small group plan and her policy contained this sort of language making Medicare mandatory and primary. In Leslie's plan, Medicare was secondary while her husband was an active employee, but it became primary when he was laid off. In Kendra's case, she has two large group plans and both she and her husband are active employees (at least on paper), so those plans are primary and secondary, and Medicare is tertiary.

In Ann's case, because this was all brought to her attention pretty early on, and the commercial insurer was reasonable to work with, we were able to get Medicare to pay the claims that her commercial insurer refused to pay. In Kendra's case, the paperwork is a nightmare and will take awhile to conclude, but the two insurers are working together and it looks like things will work out.

Leslie's case is different. The good news is that Leslie's policy does not include language requiring her to enroll in Medicare or allowing them to treat her as if she did. But it's going to be a fight. And with Leslie on disability and her husband laid off, unless we win unqualifiedly, Leslie will be in bankruptcy court unless the matter is resolved in her favor.

Brian and Mia

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I suppose it was inevitable that, working with patients with chronic illnesses, one or more of them would die over the years. Still, it's always a shock, and sometimes an outrage.

Brian had short-term disability insurance through his job. Brian had ulcerative colitis. When he had to have surgery to create a temporary ostomy – a piece of intestine pulled through the abdominal wall out of which waste drains into a bag attached to the surrounding skin by an adhesive – he applied for short-term disability benefits, and those benefits were granted. He had expected to recover from surgery, return to work, and some months later, have a second surgery to have his ostomy reversed.

Unfortunately, there were complications. In particular, Brian had wounds around his stoma – the opening of the ostomy – that would not heal. Waste was oozing out of these wounds, which had a corrosive effect, making it harder for the wounds to heal. When it became clear that Brian would not return to work as planned, and in light of the fact that a second surgery was anticipated, he was fired.

However, his short-term disability insurance was discontinued on the ground that he was able to return to work. Part of the problem was that the insurer had contacted only one of Brian's doctors, who was unaware of the complications involving the wounds, which were being treated by a different doctor. But even after we submitted a mountain of evidence – not only medical records, but photographs of the wounds that clearly displayed their disabling nature – the short-term disability plan refused to relent.

Insurance can be fully-funded, which means that the employer pays a premium to an insurance company, and the insurance company pays benefits; or self-funded, which means that the employer pays a fee to an insurer or benefits specialist to administer the plan, and the employer pays

the benefits. In this case, the plan was self-funded. Thus, in Brian's case, there was a glaring inconsistency between the employer's position that Brian was unable to perform the essential functions of his occupation – the basis for his termination – and the employer-owned plan's determination that he was able to return to work.

We filed a first-level appeal, providing medical records, a letter from the wound care specialist, the photos of Brian's wounds, and an explanation for why the other doctor thought Brian could work, and it was denied. Brian began to become very depressed. The denial letter stated that Brian was not being treated with antibiotics, which was false, as reflected in the medical records we already had submitted. We established that the delay in reversing Brian's ostomy was due to the peristomal wounds, but the insurer asserted that the delay was somehow Brian's fault. Brian had, by then, undergone the second surgery, which further extended his disability. Medical records that were submitted with his second-level appeal showed that his ulcerative colitis was, once again, active, and he was suffering from severe diarrhea. Brian's doctors had become concerned for his emotional well-being; with each letter from the insurance company, he became increasingly depressed, exacerbating his disability. Every time Brian saw a doctor, we submitted another letter with records to the insurer. Over and over, his doctors documented his ongoing disability. Time and time again, the insurer ignored the evidence we submitted and rejected his claim.

Brian's disability plan had an unusual feature; it allowed us to keep filing appeal after appeal, without limit. So I kept at it. At some point, it became as much about encouraging Brian for the sake of his mental health as it was about getting his disability benefits.

Then it came – EUREKA! We won! I was overjoyed, and called Brian immediately. He didn't answer; I was frustrated – I finally had good news,

and I couldn't deliver it. A day went by. Two days. Finally, I heard from his wife. The day before I received the good news, Brian died.

This was devastating news, of course. Brian's wife was convinced that his death was due to his abandonment of hope. He had been so beaten down by illness, by getting fired, and by the insurer's refusal to read what we were sending them that he just plain gave up. Brian had simply stopped breathing.

To this day, I remember the kick to the gut that I felt when I heard this news. If only he had hung in one more day. If only his insurance company had cared enough to get it right sooner. If only. Brian's wife and I cried together for a long time that day, and in several subsequent conversations.

Could I have done anything differently? Could I have pressed harder for a faster, sooner result? One can't help wonder.

Mia had stage four cervical cancer when a friend of hers found us. She had run out of treatment options and was being treated with the last chemotherapy drug that her doctors said was available. In addition, her only insurance was Medicaid, and her friend wondered if there was some treatment that was available that she could not access because she did not have commercial insurance. Could we help?

Knowing that we needed to think creatively, my assistant and I undertook a methodical, detailed review of every clinical trial for cervical cancer listed by the National Cancer Institute. There were fifty-four in all. Some were outside the United States, and Mia was not able to move herself to China for a year or so. She was too sick and too poor to contemplate that. Some – many, actually – required that the patient have had no prior treatment. Still, there were a half-dozen or so that looked like they might make sense.

In one of the few conversations we had with Mia – who was lovely and appreciative, but very weak and sick from chemo – we developed a protocol based on her wishes. When we found a study that looked promising, we would contact the study coordinator, find out what information was needed to determine if Mia fit the parameters of the study, and then fax the questions and the contact information to Mia's oncologist, who then would follow up with the study coordinator. We did this again and again. Each time, we were told that Mia did not qualify for the study.

When we had contacted every study coordinator associated with a study that, on its face, did not disqualify Mia, and Mia's doctor had followed up on all of them, I spoke with Mia and told her that we had reached the end of our search, at least for the time being. I promised that, in a few months, we would look again to see if there was anything new. Before we had time to do so, Mia's friend emailed to say she had died.

It is impossible not to feel that we could or should have done something else, something more, although we knew that we had done all that we knew how to do, and more than anybody else had done.

I have worked with many patients whose condition deteriorated over time, including some I've told you about. There was Martine, who was losing her vision to a demyelinating disease while we waited for a response to our health insurance appeal to obtain coverage of the only treatment anybody had recommended that had not already been tried. There was Polly, who went from Crohn's disease to Crohn's disease and gastroparesis to Crohn's disease, gastroparesis, and multiple sclerosis. Susie was an ostomate due to Crohn's disease who nearly lost her vision to iritis, and then had to have massive surgery to correct intra-abdominal hernias and adhesions that had stopped her dead in her tracks, and then got skin cancer. Chronic illnesses – especially auto-immune illnesses – come in clusters, so it

is not unusual for patients to suffer setbacks over time. But dying is a whole other story, obviously.

Do I believe that Brian's death could have been avoided? Absolutely. I've let myself off the hook – I know how hard I worked for him, and I know that I did all I could. But could his insurer have gotten it right sooner? Absolutely. Would that have saved his life? Maybe.

Could Mia's death have been avoided? Maybe. Why was it left to a friend to find us, and for us to research possible alternative treatments? Why weren't her doctors looking out for her all along? If they had been, would they have found something earlier in the course of her illness, when she might have been in a better position to meet a study protocol, or to travel? Maybe.

The system failed Brian and Mia, as it does many others. While I tell myself that it was not I who failed, still, as I write this, the tears come.

Doug

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Doug is a bright, conscientious and hard-working young man. There is no other way he would have been accepted into one of the country's top public universities. Yet, despite his intelligence and abilities, he does not hold a degree from that University. The only reason he does not have this degree is because he received no help or accommodation when he was sick due to his chronic illness, Crohn's disease.

Doug excelled in his studies throughout elementary school, middle school, and high school. Even during his senior year of high school, when Doug had to complete his work from home because of a relapse of his recently diagnosed Crohn's disease, Doug did well.

In stark contrast, Doug's undergraduate transcript is littered with incompletes, withdrawals and failing grades – an inaccurate reflection of his intelligence and abilities. The reason for this difference is that Doug's University would not do for him what his high school did: accommodate him so that he could reach his full potential.

Beginning as a full-time student, Doug started college during the 1997-1998 academic year. Still sick from his Crohn's disease, however, he ended up withdrawing from all of his classes. The next year, Doug continued to be sick but was able to complete three out of seven classes, earning nine credits for the year. By the end of the 1999 fall semester, Doug had earned only twelve credits, along with many withdrawals and incompletes. His grade-point-average (GPA) was below his standards and, because it was also below the University's standards, he was dismissed for scholastic deficiency in January 2000.

Not one to be deterred, Doug was determined to earn his college degree. He was able to enroll the following semester as a part-time, non-degree student without the benefit of his previously earned credits, so he

did. Despite the fact that he was not better physically, Doug was willing to start over again. However, because he still was not well, he could not keep up with the course work and ended the semester with two incompletes.

When Doug was feeling better, he made great strides in his studies. During the 2000 summer session and the 2000-2001 academic year, he earned eighteen credits and very good grades. It was never Doug's willingness or abilities that held him back; it was always his Crohn's disease, which unfortunately struck again during the 2001 summer session when he had signed up for four classes. His medication at the time – prednisone – stopped working and, instead, started causing him serious side effects. As a result, Doug only completed one of his classes, leaving him with twenty-one credits instead of the thirty credits that he was aiming for.

Doug's health then went from bad to worse. He signed up for three classes – or nine credits – in the 2001 fall semester, but simply was not well enough to stay on top of his work. He made every attempt to travel back and forth between home in one state and school in another, but it was a futile effort. His vomiting and diarrhea merely increased and turned out to be a prelude for something worse. For four months, from January to April 2002, Doug was violently ill. He lost a lot of weight and spent two weeks in the hospital. By the time the Fall of 2002 rolled around, Doug remained sick with absolutely no energy while his doctor tried to find him the right medication. Needless to say, Doug did not sign up for any classes during this time.

Still adamantly trying to complete his education, Doug signed up for one class in the 2003 spring semester, two classes in the 2003 summer session, one class in the 2003 fall semester, and two classes in the 2004 spring semester. Again, he was not well enough, and never was able to complete his work. At times, his professors assigned him a failing grade instead of an incomplete, even though they were made aware of his illness.

For three years, Doug remained stalled at only twenty-one credits, needing 120 to graduate. In the 2004 summer session, Doug earned another three credits for a class, for which he earned an "A," but then could not continue the momentum because he suffered another relapse.

During the 2004 fall semester, Doug was so sick that he had to go home for aggressive treatment. It was at that point that his University, taking into account all of his incompletes, withdrawals, and failing grades, dismissed him from school. They did not, however, take into account the reason for all his incompletes, withdrawals and failing grades – his Crohn's disease.

This is where I came in. Doug and his parents contacted me and asked for help. We managed to contact someone at the University who told us that Doug would be able to finish his coursework for the classes that were marked as incomplete, and have failing grades changed to withdrawals, provided that Doug approached the professor for each one of his classes individually. This was no small task considering the number of classes in which Doug had earned incompletes and failing grades.

Throughout the following year, both Doug and I attempted to reach out to his professors. It proved to be an arduous and cumbersome task. Some of the professors no longer worked at the University, some never returned our emails or calls, and some simply were not sympathetic to Doug's situation. Doug was not looking for sympathy; however, he was looking for help and accommodation so that he could do the work he needed to do in order to earn back his credits – credits, by the way, for which his parents already had paid.

Doug and I tried our best to track down his professors, and Doug tried to complete his work or retroactively withdraw from some of his classes, but the school did not offer the support he needed to take on such a laborious task one professor at a time. In fact, in response to my request to

streamline the process and to help make Doug's efforts more efficient, the University's Office of Diversity and Equity (ODE) stated that they were not only, "not an advocate for students or employees with disabilities," but also that, even though, "[I] perceive[d] the procedure to be burdensome," ODE, "[was] not in the position to alter the procedure or to assist in carrying out the steps under the procedure." Apparently, it was no one's job to advocate for students with disabilities. Over a period of years during which both I and Doug tried to clean up his transcript, no one at the school ever tried to step in and help Doug complete his education.

Even worse than not employing anyone or any office on campus to advocate for students with chronic illnesses, however, is that the University also did not want anyone else advocating for Doug. Consistently insisting that Doug be the one to see his professors for his work and/or to get them to sign the forms he needed to retroactively withdraw, they would not allow either me or his parents to help him beyond getting the instructions telling Doug what he needed to do, the names of the teachers who had taught the courses in which he had gotten incompletes, and the identity of department Chairs to contact instead of the professors who had left the University.

During a 2006 attempt to return to the school to meet with professors, Doug had a car accident and broke his leg and could not drive to campus. Still, the University maintained its hard line – Doug had to speak with his professors in person, and neither I nor his parents could do so in his stead.

Doug wanted to complete his education at this University, but could not jump through the hoops that were required of him. By prohibiting Doug's parents or me from helping Doug gather the forms and signatures he needed to complete his work or change failing grades to withdrawals, Doug was set up to fail. He never was physically able to track down all of his professors by himself, which meant that he never was able to complete the

work he was willing to do or get the failing grades off his transcript, and as a result, he never finished school.

It is worth highlighting that this was a *public* University, one clearly bound by the Americans with Disabilities Act (ADA) and state anti-discrimination laws. With some help and accommodation from his school – help and accommodation that he should have received pursuant to these laws – there is no doubt that this intelligent young man, although afflicted with a horrible chronic illness, not only would have graduated, but would have done so at the top of his class.

Diane and Roger

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Diane (African-American female) and Roger (white male) suffer from unbearable depression. Both have worked on and off over the years, but ultimately, have been unable to maintain employment for a protracted period. Diane is on Medicaid, and Roger has private insurance through his wife's employer. Both have been seeing psychiatrists for years, and both have tried all manner and means of pharmaceutical therapy, with no lasting results.

Diane was functional, though. She was determined to find an answer. Her husband had HIV, and she wanted to be there for him. She fought for her Medicaid eligibility. She fought for her husband. And she fought for herself.

Roger was unable to fight for himself at all. He was tearful, always. He had been involuntarily committed several times due to suicidal ideation, and he had undergone several rounds of electric shock therapy.

Diane and Roger saw different doctors, but at right about the same time, both of their doctors suggested that they try a surgically implanted device called VNS, or vagus nerve stimulation. This is a small electronic device that is implanted in the chest, with leads that reach to the vagus nerve in the neck. This device has been used with good effect in treating epilepsy. However, its use in treating depression is not widely accepted – by insurance companies.

In Diane's case, the problem most likely was insurmountable. As a Medicaid recipient, there really was no chance that VNS would be covered. Despite the fact that VNS therapy was FDA approved in 2005 based on findings that it is both safe and effective for treating depression when all other modes of treatment have failed, Medicaid reimbursement for new and expensive devices – especially for the treatment of mental illness – is longer

than a long-shot. Diane came to us shortly after the device was approved. We met with representatives of the manufacturer, Cyberonics, Inc., we talked to the state Medicaid Director, and determined that we should start with Roger's case first. If we had luck with commercial insurance, then perhaps we would try Medicaid.

However, we were stopped dead in our tracks for several reasons. First, Medicaid decided that Diane wasn't really eligible. The state claimed that she was over the income limits, and that she could not show that she had spent enough on medical expenses so as to "spend down" her income. We then became enmeshed in a protracted battle just to keep Diane on Medicaid.

In Roger's case, his long-term disability benefits were terminated. Under his disability insurance policy, Roger not only had to show that he was unable to work, but because his was a mental health disability, his doctor had to either institutionalize him for the long term, or submit an "extended treatment plan" to the insurer to show that he was trying to get well. The disability insurer had written Roger's doctor and given him a deadline for submitting a plan, but he never did. If Roger had a physical illness, he would not have had to meet this requirement, but because he had a mental health disability, he had to jump through a much narrower hoop in order to retain his benefits.

We submitted documentation to show that Roger was admitted to a partial hospitalization program at a residential psychiatric facility, where he spent his days, going home in the evenings. We presented evidence that he had undergone electric shock therapy and would continue to do so as needed. Roger's doctor's notes showed that the long-term treatment plan was psychotherapy, electric shock therapy, medical therapy, and, if possible, VNS.

The disability insurance company denied our appeal. First, we could not show that this extended treatment plan was in place at the time when the insurer discontinued benefits; it was a plan that had been developed later, when Roger's condition continued to deteriorate, and when Roger's doctor finally agreed to assist us by putting the plan he had in his mind on paper. Second, we could not show that Roger's insurance would cover VNS.

In our efforts to beef up the extended treatment plan, Roger's doctor did submit a request for prior authorization for implantation of VNS. Roger's insurer denied the request. At the time, because the device was so new, all we really had to rely on was the FDA approval and the studies that had formed the basis for this approval. Despite the FDA's finding that the device is safe and effective, the insurer concluded that the device was "experimental, investigational, or unproven."

Although we had every intention of appealing this noncoverage decision, the inability to have Roger's disability benefits restored because the extended treatment plan was presented to them in August instead of April, when the insurer first asked the doctor for it, knocked Roger for a loop. He had no interest in fighting. He did not want VNS. He just wanted to be left alone.

In both Diane and Roger's cases, we never got far enough to appeal the decisions to not pay for VNS. Despite FDA approval, the manufacturer candidly told us that very few insurers were covering VNS, and no state Medicaid program had covered it, at least at that time, which was within a year of FDA approval. Although I do not understand the logic that permits an insurer to claim that a treatment is experimental despite full FDA approval, many insurers have taken that position with respect to VNS. Indeed, the manufacturer's website acknowledges that, even today, reimbursement is hard to come by. There was no point, especially at that

early stage of the device's availability, in pushing Diane's Medicaid claim when only a handful of payers had covered the device.

Why could insurers deny coverage despite FDA approval? My best and only answer is that mental illness is not treated the same as physical illness for insurance purposes, even in states that have laws that require parity of mental and physical health benefits. The mentally ill suffer from unspoken bias; the silent implication is that they ought to just get their act together and move on with their lives, as if it were a choice to suffer from paralyzing depression.

These two snapshots illustrate the fact that this is inequitable. Diane was no more equipped to fight Medicaid than she would have been had she had a physical illness. Roger was so depressed about the loss of his disability benefits that he could not afford to assume the risk of losing another insurance battle. In both cases, the obstacles – which were greater than the obstacles faced by patients affected by physical chronic illnesses – were so great that getting coverage for a new, expensive device became a secondary priority, even though it might have resolved both patients' depression. The obstacles to accessing care were just too great to overcome, so both patients did not receive the care they needed.

Molly and Milly

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Enterra Therapy, or gastric electrical stimulation, often is referred to as a gastric pacemaker. That's a bit overly simplistic. Patients with gastroparesis (like me) have paralysis of the stomach muscles, so instead of food being mashed up and processed in the stomach, it just sits there. As a result, gastroparetics are constantly nauseated, and suffer from vomiting many times a day, as well as abdominal pain. The device isn't really a pacemaker; it doesn't make the muscles in the stomach contract. Instead, it stimulates the vagus nerve, which, in turn, stimulates peristalsis and, thus, helps to control nausea and vomiting secondary to gastroparesis. As is the case with many treatments for many chronic illnesses, it treats the symptoms, but not the underlying disease, for which no treatment is known.

Although there are a relatively few people in the United States with gastroparesis, I got involved with Enterra because a dear friend of mine has the device, and it saved her life. Long before I began to think I was showing signs of delayed gastric emptying, we had developed a sort of cottage industry of filing insurance appeals on behalf of people whose insurer won't cover Enterra.

Because fewer than 4,000 units per year are implanted, the manufacturer of Enterra applied to the FDA for a humanitarian device exemption, which means the FDA has found the device to be safe, the benefits of the therapy exceed the risk, and the medical rationale for the use of the device is sound – not the full pre-market approval the device would get if larger, more costly studies were done to prove the device's effectiveness. Because of this FDA second-class status, insurers have gotten away with considering the device to be "experimental, investigational, or unproven" – a policy exclusion in most cases.

My friend got the device as part of a study, so she hadn't faced this problem with insurance coverage. However, by now, we have handled about seventy files in which insurers denied coverage of Enterra. In some of those cases, for a variety of reasons, the patient decided not to go through with the surgery, ranging from fear associated with having a device implanted in the body, to a family that became convinced that the patient had anorexia rather than gastroparesis. But of the 50 or so appeals we have filed, we have won approximately 90 percent of the time. To me, that means that insurers are denying coverage way too often; and people who don't find me may not be getting the treatment they need.

Molly is a nurse in Connecticut. Milly worked for a disability insurer in Connecticut. They both had UnitedHealthcare insurance, although Milly's was self-funded, which means the employer pays an insurer to administer the plan, but actually pays for the health care itself, whereas Molly's plan was fully-funded, which means the employer pays an insurance premium and the insurer pays for the health care itself.

Both Molly and Milly were in their 30's. Neither was married. They both had gastroparesis, and both had severe nausea and vomiting. But there were significant differences between them. First Molly was insulin resistant. Gastroparesis often occurs in diabetics, and when it does, it makes it very hard to control blood sugar because you can't control food consumption. Although Molly did not have diabetes, her insulin resistance strengthened her claim. Second, Molly was eating only clear liquids; her next step was a feeding tube. Milly's gastroparesis is idiopathic, like mine, which means nobody knows why we have it.

But here's the kicker. Milly told her doctor fairly early on that she'd done her research and she wanted Enterra, and her doctor wrote it down and included it in his treatment notes. Milly didn't want to try anything else; she just wanted Enterra. She ended up trying everything else before the

insurance company ultimately denied coverage of Enterra, but there was that big, bold statement in her medical records, and I knew the minute I saw it that we had a problem.

Sure enough, Molly's appeal was granted, and Milly's appeal is one of only two UnitedHealthcare Enterra appeals I've lost. At the hearing at the final level of review, the medical director expressly asked Milly about that statement in her medical records. Even though we explained that, after making that statement, she really did try everything else, that one line really hurt our chances, as I knew it would. Any sign that the patient is making the treatment decisions – which, in my view, is a good thing when a patient does research and can converse with the treating physician as an active partner – and the insurance company says no. I am convinced that, absent that statement in her records, Milly's appeal also would have been granted.

Another aspect of obstacles to coverage of Enterra involves Medicaid. Here in Connecticut, we had two patients who were on Medicaid. The surgeon called me and asked me to help. I have done a couple of Medicaid appeals for Enterra in other parts of the country, but since I know that, in Connecticut, Medicaid appeals end up in court, and that goes beyond what we at Advocacy for Patients do, I contacted a Legal Services attorney who agreed to take the cases. However, instead of doing formal appeals, she got newspaper coverage, which was not what I was hoping for. Both the doctor and the hospital immediately said they would do the procedure for free, and I got the device manufacturer to donate devices for them. Why was this a bad outcome? I was hoping that this Legal Services lawyer would establish a precedent for other patients into the future. Instead, we got these two cases handled – an excellent outcome for them – but we are back at square one for Medicaid coverage of Enterra in Connecticut.

The majority of Enterra appeals involve commercial insurance. I've handled fewer than a half-dozen Medicaid cases, and roughly the same

number of Medicare cases – but only through Medicare Advantage Plans. Medicare Advantage Plans are private HMOs that are paid a per diem rate by Medicare to provide members with any and all services they need. In other words, they are Medicare managed care plans. Their rules about what to cover and what not to are very different from traditional Medicare's – a fact most enrollees don't know.

The appeal process for Medicare Advantage Plans starts with the Plan itself, and then moves to a second level appeal by a federal contractor called Maximus – which also processes traditional Medicare appeals – and on up to an Administrative Law Judge and, ultimately, to court. We never have had to go beyond Maximus for an Enterra appeal; we have won most of them at the Plan level, and have gone to Maximus only a couple of times.

Enterra is a really good example of what's wrong with our system. Almost every insurer requires that the surgeon obtain prior authorization before most surgeries, including implantations of Enterra therapy. If the doctors took the prior authorization stage a little more seriously and sent a patient-specific letter of medical necessity with some basic medical records establishing the diagnosis and the attempts to treat the problem medically rather than surgically, I suspect there might be fewer appeals. Indeed, if insurers took this stage more seriously and asked a few questions, and requested whatever medical records they feel they need, there would be fewer appeals, too. But surely, if we are winning roughly 90 percent of our Enterra appeals, then insurers are denying Enterra far more frequently than they should.

What we do differently in the case of Enterra (and most other health insurance appeals) is that we gather all of the patient's medical records. In addition to the test that confirms the diagnosis of gastroparesis – a gastric emptying test or GET – we include office notes showing what medications were tried and failed, and how much weight the patient lost. We also

enclose test results that exclude other diagnoses. For diabetics, we gather records from the endocrinologist as well as the gastroenterologist to show that the patient's diabetes is out of control and cannot be controlled without also controlling the patient's food intake.

In addition, in all cases in which an insurer claims that a treatment is "experimental, investigational, or unproven," we enclose medical journal articles. In the case of Enterra, there are voluminous medical studies. Further, we attach copies of every letter we have received granting our appeals – letters from UnitedHealthcare and its affiliates, Blue Crosses around the country, Coventry and its affiliates, Humana, Medicaid, Medicare, Chrysler, General Motors, independent review organizations, and the plans that cover employees of the United States Postal Service and the federal government.

So our appeal packet usually equals approximately 350 pages of material showing (1) that Enterra is safe and effective; (2) that the patient really needs it; and (3) that most insurers pay for it once we appeal, and the ones that don't are forced to do so by independent review organizations that review cases at the behest of state insurance departments. At this point, our appeals are being granted in under two weeks. I wonder if insurers just see the volume of paper and decided we must know what we were talking about!

I can't conclude the tale of our Enterra appeals without acknowledging some of the other patients we've served. Leroy was so sick that he was going to the emergency room two or three times per week before he got to me. Doris and her mom were so grateful, after fearing that Doris would die of starvation, that they made me a beautiful quilt. And now, the top motility doctors in the United States refer patients to us directly.

Ultimately, I hope, the insurers will tire of reversing themselves or being reversed by independent reviewers. In particular, there simply is no

justification for UnitedHealthcare to continue to deny coverage of this device and grant every single appeal I file with them with only two exceptions. The harm to the patients of delaying treatment long enough for me to collect their medical records, pull the appeal together, and finally get a decision is inexcusable and must end.

But it won't be fast enough for 22 year old Jill, whose mother called me this morning and thought I would just call the insurance company and make them change their minds. After all, they had traveled all the way from Buffalo, New York to Cleveland, Ohio to have the surgery, which was scheduled for tomorrow. When I explained that I needed a release and medical records, she burst into tears. Her daughter is a full-time student, and that is the only reason she is able to stay on her parents' health insurance. If she doesn't have the surgery NOW and start back at school when the new semester begins in about 10 days, she no longer will be a full-time student and will lose her right to be on her parents' health insurance. Still, I have no way of appealing without sending the insurer a release signed by the patient, and gathering the patient's medical records so that I can show that she has tried every other treatment available. I am fast, and I am willing to drop everything for an emergency, but I am not a magician.

As I write this, this family is in crisis. The surgeon is going to try a "peer-to-peer" tomorrow, meaning a discussion between the surgeon and the medical director at the insurer who is denying coverage. If that doesn't work, the family will move heaven and earth so that I can get medical records faxed to me and get the appeal out immediately. But that doesn't guarantee that the insurer will review it overnight. Indeed, even an expedited appeal takes at least 72 hours from when it is received by the insurer. Unless the "peer-to-peer" works – and they rarely do with this device – I doubt that Jill will be approved before classes start for next semester. So either she enrolls in classes and hopes she can figure out some

way not to fail them all because she has to have surgery mid-semester, or she waits to have surgery until the summer, all because the insurer didn't process the request for prior authorization faster, and because Jill will lose her insurance if she takes a leave of absence from school. The ultimate Catch-22.

Patients who need Enterra therapy have tried all medical alternatives. The lack of treatment will mean a feeding tube or death. But because the manufacturer got a humanitarian device exemption instead of full pre-market approval, insurers deny coverage, and at least some of the patients who don't find their way to me will die as a result. In what universe is this not wrong?

Gary

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Gary has Crohn's disease and misses a fair amount of school as a result. His father is in the Army, currently deployed to Iraq, leaving his mom to deal with the school, which is particularly rigid in their policies.

At first, the school refused to provide any accommodations of this child's disability under section 504 of the Rehabilitation Act of 1973 on the ground that the disability does not affect the student's ability to learn. Then I got involved and pointed out that section 504 does not require a showing that the physical disability results in a learning disability, and they agreed to write a plan of accommodation. However, negotiation of the plan terms was painful and slow. Finally, though, we resolved most of the issues.

The most difficult issue to resolve was what to do when the student misses school due to illness. We were able to agree on provisions that address instances when the student misses a couple of days of school. Where we got stuck was on what to do when the student is out for a longer time – a week or two – and falls behind in his work.

When the family was based elsewhere, the parents would simply notify the school if the student was going to be absent for a few days, and the school would provide instruction on a daily basis. The teachers would send home outlines and assignments, and provide some tutoring, thereby allowing the student to remain current in his class work.

The school district's policy for "homebound instruction" says that, when a student is out for 20 or more consecutive school days, homebound instruction in the form of one hour of tutoring per week is provided. Not only is one hour per week insufficient, but requiring that the student miss a full month of school before qualifying for homebound services is a guarantee that the student will fall far behind before getting any help.

The school hired a lawyer to negotiate this point. We ended up with a plan that provides that, if the student is out for 10 consecutive days, he is eligible for homebound services. We did not make any progress on the number of hours of tutoring per week, but at least we made sure the student could get services sooner.

Then Gary broke his shoulder and was absent for 10 days. His mom didn't think much about the school issues because the absences had nothing to do with his Crohn's disease. Gary went back to school after Thanksgiving for about three weeks, at which point the school called the mother in, ostensibly just to go over where the student stood in his classes.

Instead, she got ambushed by the entire 504 committee, which voted to place the student on homebound instruction whether he and his parents liked it or not. This was after he had returned to school for awhile and was doing fine, and was entirely capable of attending school.

And here's the kicker. The school essentially kicked him out of school and confined him to his home, but refused to provide homebound services without a doctor's note indicating that he needed the homebound services due to his illness. The doctor refused to write such a note because the student did not need homebound services due to his illness at the time because his illness was in remission. So really, the District kicked him out of school but refused to provide homebound services, which is tantamount to expulsion without a hearing or any opportunity to object.

The District actually takes the position that, if the child is absent alot, it cannot provide educational services to him, so he should be on homebound instruction. Where the logic is in this, I don't know. It's not like he would get any real instruction on homebound; one hour a week surely isn't a substitute for going to school every day. And when the child is healthy, he ought to be allowed to attend school. Any other rule deprives the student of his right to a free, appropriate public education.

The school's lawyer – bafflingly – defends the school's position on the ground that the school has to provide the student with an education, and it can't do so if he doesn't come to school, so therefore he should not come to school if he wants educational services!!! That's really what she said. "[T]he District has an obligation to provide educational services to [Gary], which the District is unable to do based on [Gary's] numerous absences. Accordingly, as [Gary's] 504 team determined, his most appropriate placement is homebound." I swear this is true. I'm not creative enough to make this up.

To break the impasse, we then presented the District with a doctor's note saying that Gary was medically cleared to attend school. Now, according to the District and its lawyer, we have to wait for the school to convene another 504 meeting so that the 504 committee can vote to allow the student to return to school. The student is falling behind every day, and we simply have to wait until this large group of teachers and administrators can clear their schedules so the child can return to school.

Since when are the civil rights statutes intended to be used to prevent a disabled student from attending school when he's feeling well enough to do so? How can a school use its obligation to provide this young man with an education as an excuse for kicking him out of school? This perversion of the law is nothing short of insane. Yet, our recourse – filing a complaint with the U.S. Department of Education Office of Civil Rights, which we may still do if we cannot reach agreement with the District on how this will be handled in the future – would take months, at the least, to have any positive effect. In the meantime, we have to continue to press the school to allow the student to attend classes or he will fall further behind.

How dare we punish children for being sick?

Hilda

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Hilda was referred to me by a lawyer friend. She worked for an insurance company. She is a very smart, capable, professional person who seemed like she probably was a very good employee. Until she got sick.

When she came to me, Hilda had been on short-term disability for what began as a general feeling of malaise, but with no conclusive diagnosis. She tested positive for the Epstein-Barr virus (basically, mononucleosis). She also had near constant headaches and several incidents of syncope (fainting). In addition to the positive Epstein-Barr titers, Hilda had several immune deficiencies that appeared on her blood work. She had impaired memory and cognition, painful joints, and unrefreshing sleep confirmed by a sleep study. A tilt table test showed autonomous dysfunction, and she was dizzy.

After five months of short-term disability, her insurer terminated her benefits on the ground that she no longer was disabled. This was a unique situation in that her employer also was her disability insurer. When her employer terminated her disability benefits, it also demanded that she return to work immediately or be fired. Since she was unable to return to work, she lost her job. I have never seen a clearer conflict of interest by an insurer.

According to the Centers for Disease Control, to get a solid diagnosis of chronic fatigue syndrome, the patient has to have symptoms for six months. Thus, when Hilda first went on disability, and when she lost her benefits and her job, she did not have this diagnosis, but by the time we filed our appeal, she did.

What she did not have, though, was a strong doctor whose office notes reflected a clear picture of Hilda's condition. As often is the case with chronic fatigue syndrome, the insurance company denied continued

disability because there were insufficient objective findings. The insurer did not dispute the diagnosis of chronic fatigue syndrome; instead, it disputed Hilda's claim that the effects of this illness were disabling.

During the course of our appeals, Hilda's primary care physician moved his practice and then packed it up and quit, making it difficult to get records from him, and making it impossible to get him to write a letter of support. Hilda found an alternative medicine specialist who did not carry much weight with the insurance company, and who was trying to treat her symptoms without success. I have won several disability appeals for patients with chronic fatigue syndrome, but the doctor I had worked with geographically closest to Hilda would not make time in her schedule to see Hilda. Without medical records, it didn't matter how Hilda felt; we couldn't prove it.

This was compounded in this case by the fact that the insurer sent a copy of its reviewer's report to three of Hilda's doctors, none of whom responded in any way – and none of whom let Hilda know they had received this report. Had we known that this report was out there, we could and would have found someone – even if it were Hilda's primary care provider rather than a specialist – to dispute the reviewers' opinions. But without that knowledge, and without a supportive medical professional with clear records and the willingness to advocate with the insurer, our appeal was denied.

Hilda is angry, depressed and sick. She doesn't work because she can't. She has no income; her employer/insurer saw to that. She went from being an over-achieving professional to being disabled by an illness that is invisible to everyone but herself.

And her employer/insurer got rid of both an expensive employee and an expensive insured with one stroke of the pen.

Nina, Zelda and Marvin

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One of the new trends we have seen in insurance company denials is the imposition of requirements that patients try a list of other medications before the insurer covers the treatment that the doctor prescribes. Some people call this "step therapy." This trend is evident in several cases involving prescriptions for intravenous immunoglobulin (IVIg) for relapsing remitting multiple sclerosis (RRMS), as well as other cases.

Nina has RRMS. Typically, patients with RRMS are on some form of interferon, and Nina is no exception. However, interferon has not proven to control her illness when taken alone. She had tried intravenous Solu-Medrol, a steroid, with no benefit. Her doctor suggested intravenous immunoglobulin (or IVIg) along with interferon, with interferon acting as a disease modifying agent, and IVIg serving to lessen remission and restore myelin. For a year, Nina's insurer paid for IVIg and interferon, and NP did extremely well, having no problems walking and working full-time.

After that year, though, her insurer abruptly decided that it no longer would cover her IVIg. All of a sudden, IVIg was considered experimental and not medically necessary, despite the fact that it had been shown to control Nina's disease activity for a year, and despite numerous medical journal articles supporting the use of IVIg to treat RRMS. The insurance company stated that it would have to see proof that IV Solu-Medrol did not work before it would consider approving IVIg. This was so despite the fact that IV Solu-Medrol is known to have side-effects including acne, weight gain, seizures and psychosis, and, thus, it is not recommended for long-term use. In other words, you might use IV Solu-Medrol to curtail a flare, but not as a long-term treatment.

In Nina's case, because she had tried IV Solu-Medrol and had suffered an adverse reaction, we were able to document the inadequacy of

that drug. In addition, Nina's medical records showed great improvement clinically and on MRI while she was on IVIg. However, as soon as IVIg was discontinued, she began to have difficulty walking, and feared that her ability to work would be short-lived.

I filed our first appeal, outlining the course of Nina's disease, which showed quite clearly that several forms of interferon had been tried, and none curtailed her disease when administered alone. Medical records documented the adverse reaction to IV Solu-Medrol, and scored her symptoms to show that they had worsened while the IVIg was discontinued. The insurance company – for reasons having nothing to do with Nina's health – granted our appeal for a short period of time, but said that, if we wanted additional treatment, we would have to demonstrate continued medical necessity. The unstated reason our appeal was granted was that the insurer was not a utilization review agent licensed in the State and, thus, was not permitted to make medical necessity determinations. Since they had violated state law, they granted benefits for a short time in order to attempt to clean the slate.

When this brief authorization expired, the doctor's office submitted additional information supporting the need for IVIg, and the insurer once again denied coverage. Once again, it acted as a utilization review agent, making a medical necessity determination, although state law prohibited it from doing so. The insurer then took the novel – and wrong – position that we had exhausted our appeals although this new request for prior authorization involved entirely new dates of service. After much correspondence and discussion, the insurer agreed that we had a right to appeal this new denial, but stated that our appeal had to be directed to the State. We contacted the State, which told us quite clearly that this was wrong, that the insurer had to have an internal appeal mechanism that had to be exhausted before we could appeal to the State. Despite all of this, the

insurer once again denied our appeal on medical necessity grounds, and then granted coverage of six months of treatment as an administrative decision because its denial once again violated state law. Once again, the insurer was looking for a clean slate.

At the end of six months, the doctor once again sought prior authorization of IVIg. By now, these appeals had been ongoing for about nine months, during which Nina had to endure months at a time without her IVIg, while I proved to the insurer that it was serially violating the law. This time, the insurer used an outside utilization review agent to consider our appeal, and again denied coverage on the ground that IVIg was experimental for treating RRMS, and that it was not medically necessary. This was so despite updated medical records that showed quite conclusively that Nina did well when on IVIg and poorly when she was denied access to this treatment.

We then filed an appeal through the State and won – two weeks before Nina's employer was changing insurers. In all, Nina was without medically necessary treatment for five out of twelve months while her insurer flouted state law. The insurer's insistence that Nina try IV Solu-Medrol is what started this whole debacle; however, in the end, even after we proved that Nina had, in fact, tried and failed IV Solu-Medrol, the insurer went to great lengths to prevent Nina from getting the only treatment that maintained her ability to work. In my opinion, this is evidence that the insurer wasn't really concerned that Nina try Solu-Medrol before they would cover IVIg; the insurer simply didn't want to pay.

Zelda's case is even more egregious, if that can be believed. Zelda has RRMS and was on IVIg for four years when her insurer – a different insurer – terminated coverage of this treatment. We submitted voluminous documentation showing that Zelda does well when at her peak of IVIg therapy, but when it is time for her next treatment, she becomes

symptomatic. The insurer denied our appeal because we did not show that she had tried a whole list of other medications. Because Zelda has anticardiolipin/antiphospholipid antibody syndrome (a precursor to lupus), lesions on her liver, depression, fibromyalgia, high cholesterol, and high blood pressure in addition to RRMS, many of these other medications were contraindicated. For example, we obtained a letter from Zelda's liver specialist stating that interferons and a biologic called Tysabri were dangerous for Zelda because of the lesions on her liver. Indeed, the prescribing information for each of the drugs the insurer listed demonstrated that none of them was safe for Zelda in light of her co-morbidities.

What was truly remarkable about this action by the insurer was its assertion that it had a "fiduciary obligation" to Zelda to make sure that she had tried all of these other drugs before approving the one and only medication that had kept her RRMS in check for four years. Indeed, even after we proved that Zelda had tried some of the medications the insurer listed, and that the others were contraindicated, the insurer insisted that Zelda seek a second opinion before it would approve additional IVIg therapy. And even after a second doctor opined that IVIg was the right treatment, the insurer balked. Clearly, there is no "fiduciary obligation" that flows from insurer to insured. Doctors have the judgment to practice medicine, not insurance companies.

A patient advocate who works with patients with immune deficiency tells me that she is seeing this pattern of insurers requiring that patients try a long list of other medications before they will cover IVIg pretty regularly these days.

Zelda is getting her IVIg, but we are getting approvals one year at a time, and most likely will have to mount a fight on an annual basis. Her

doctor quit on her because he found that the interference by the insurer was intolerable.

Imagine what must happen to the patients in the same boat as Nina and Zelda who don't have a lawyer to champion their cause. I have to wonder how many people with RRMS who are on Social Security disability would be able to work if only they had been able to get the treatment they needed when they needed it.

I recently read about a woman who was on Celebrex for joint pain for some time. Her insurance company then, all of a sudden, told her she no longer could have Celebrex until she tried aspirin, Motrin, Advil, and other over-the-counter medications, all of which she had tried before she went on Celebrex in the first place. Rather than fighting with her insurer, she decided to just play by their rules, so she tried each of the over-the-counter pain medications for a few weeks, and ended up back on Celebrex.

Shortly after resuming Celebrex, though, she began to feel pain in her chest. It was a sharp pain, lower than her heart, and there was no radiation to the left arm or other indication of a heart attack. Still, when the pain would not go away, she went to the emergency room. It turned out she had developed eight ulcers and was bleeding internally. The insurance company then had to pay a $14,000 hospital bill instead of the cost of Celebrex for the few months when she was on "step therapy."

Marvin has Barrett's esophagus and, thus, has to take a proton pump inhibitor (PPI) to alleviate inflammation. Over a period of years, Marvin has tried all of the PPIs and found only one that worked and did not have debilitating side-effects. In 2002, Marvin's insurer made him try a list of PPIs before it would pay for the one that finally worked. Marvin did so. Then again in 2006, the insurer made him try the whole list yet again, which he did, ultimately obtaining approval for the medication that works. But again in 2008, the insurer demanded that Marvin try the whole list of PPIs a

third time. This time, we documented the fact that this was the third time the insurer was forcing Marvin to undergo this same process, reaching the same result each time. The insurer insisted on medical records showing that the other PPIs didn't work or had bad side-effects, so we gathered records going back to 2006 and even earlier to try to document that which Marvin had related to his doctors primarily by telephone, so that documentation was hard to come by. Ultimately, we succeeded, but not without a tremendous effort. And who knows how long it will be before Marvin's insurer starts this all over again.

One element of health care reform currently under discussion contains funding for Comparative Effectiveness Research (CER). The goal of CER is to determine whether expensive new treatments really are any more effective than less expensive, traditional therapies. CER is being authorized for the Medicare program, but you can be sure that commercial insurers will rely on CER to avoid paying for new, expensive medications. But if you are Zelda and have lesions on your liver, less expensive therapies may be dangerous, and since CER is not patient-specific, it's highly likely that you would have an even harder fight with your insurer if their denial was supported by CER.

Expect to see more of this sort of thing as the cost of prescription drugs continues to rise.

In my view, this is one of the scariest trends I have seen. It used to be that insurers were very careful not to cross the line into practicing medicine. Even now, an insurer will send a letter listing other medications a patient must try before the insurer will cover the prescribed treatment, still stating in the letter that the insurer's decision is only a coverage decision, and is not a decision on treatment. However, when an insurer requires that a patient with RRMS and lesions on her liver try Tysabri, which carries with it a "black box warning" from the FDA because of its potentially life-

threatening side-effects, before the insurer will cover a treatment the patient has been on for more than four years with excellent results and no side-effects, the insurer is prescribing. Insurers who continue down this path do so at their peril.

But really, the harm is felt by the patient most of all.

Jill

Jill is the mom of an 8 year old girl with diabetes. Several times a day, her daughter's blood glucose must be monitored, and insulin must be administered before lunch and whenever else her blood sugar dictates. Jill lost a stepchild to illness, and so is hyper-vigilant about her daughter's diabetes. This has, at times, created a strain in the relationship between Jill and the school and, in particular, the school nurses.

Jill was referred to Advocacy for Patients with Chronic Illness by staff at Connecticut Children's Medical Center. For several months, Jill would call and report an incident about which she was unhappy. We essentially served as her record-keeper. However, on two occasions, when Jill felt that the school nurse had violated the established protocol, she asked us to write a letter to the school, and we did so. On these two occasions, a person unknown to Jill had administered insulin to her daughter, and Jill was concerned because this person not only was unknown to her, but, she feared, was not trained in her daughter's protocol.

As a result of our intervention, the school hired an attorney, which meant that we no longer could communicate with the school directly.

At about the same time, the school commenced the process of developing a Section 504 plan and an individual health care plan for Jill's daughter for the next school year. The school's first draft was more than 20 pages. Half of it was a plan for how the school was going to teach Jill's daughter how to manage her own illness – at age 8, and independent of her parents – and the other half laid out the treatment protocol, allowing the school direct access to Jill's daughter's doctors, requiring all changes to the protocol to be approved in writing by a doctor, and excluding Jill from participating in her daughter's care. Essentially, they didn't want to deal with Jill at all; they wanted to take over her daughter's care during the

school day. Termination of parental rights without anything resembling due process.

We countered with a plan of our own. We began with a compromise, allowing the school to teach Jill's daughter some care management, but not allowing the school to decide when Jill's daughter was able to self-treat without her parents' consent. We offered to have the doctor confirm changes in the treatment protocol after the fact, but required that the school implement changes based on Jill's instructions. We did our best to draft a plan that was consistent with the school's intent without violating Jill's parental rights and responsibilities.

However, Jill had two major concerns with the way the school had structured the plan. First, she wanted to know who would be treating her daughter. She wanted to make sure that all treating personnel were trained properly and knew her daughter's protocol. Second, she insisted on her ability to make changes to the treatment protocol, which her daughter's doctors repeatedly had told the school was entirely reasonable and appropriate. Changes to a diabetic's treatment protocol such as increasing the number of ounces of juice to administer if blood sugar is low are made on a regular, ongoing basis. Jill had been educated by her daughter's doctors on how to treat low blood sugar and high blood sugar, and in the ordinary course, the parent then would be responsible for the day-to-day details of her daughter's care.

Although we never will know with certainty whether it was the lawyer or the school that held up the process, we did not get a response to our counter-proposal for more than a month. During that time, Jill had issues with the school that had to be addressed. The school's lawyer was particularly bad about returning phone calls, emails, and letters. The brick wall that this created infuriated Jill, and my job morphed from advocate to mediator, as I tried to keep Jill's mind open, willing to negotiate for

something less than perfection. Where Jill once was interested in compromise, that spirit eroded over time to the point at which she no longer was prepared to give the school as much ground as we initially had proposed.

Whether due to Jill's promptings or not, just at the point at which Jill ran out of patience, her daughter's doctors also decided that they would not be put in a position of having to approve every change to the treatment protocol in writing, whether before or after the change was implemented. Connecticut Children's Medical Center wrote a letter to the school, copied to me, refusing to play that role.

We ended up with a plan that permitted Jill to make changes to the treatment regimen in writing; that permitted the school to speak to Jill's daughter's doctors only with Jill's permission; and that eliminated all disease management training by the school, leaving this to Jill – in essence, everything Jill wanted. However, it took months for us to get to the point at which we started. There was no reason for the school to spend money on a lawyer, waste huge amounts of staff time, and indelibly harm the relationship between the parent and the school, and especially the nursing staff. They could have accepted our proposal in the first place and avoided all of these negative results. Unfortunately, what could and should have been an opportunity for the school and the parent to work together to help this young child get the care she needs during the school day became a protracted and painful process that adversely affected all of the participants.

And then comes the need to enforce the plan. I fully expect to hear from Jill in the future.

Why do schools fight over things that cost them nothing? I realize that Jill may be somewhat hyper-vigilant about her daughter's care, but it's a lot better than being neglectful. Jill was not, in my opinion, unreasonable in

the slightest. Most parents aren't. They just want their kid to have a level playing field and not be punished for being sick.

I recently got a call from a parent whose son is 14 years old. He was not feeling well and put his head down on his desk. He was suspended for a week. The school decided he was going to the bathroom too often (he has inflammatory bowel disease), so they put him on "lock down," refusing to allow him to use the bathroom during classes. Inevitably, he was incontinent and the school sent him home.

One school hired a lawyer to fight with me over giving a child an anytime bathroom pass. The lawyer reviewed the file and told the school to give the kid the pass. Of course!

These are our tax dollars at work. Hiring lawyers to fight over a bathroom pass.

Juanita

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Juanita has a teen-ager with an undiagnosed digestive disease as well as congenital CMV infection, hypertonic cerebral palsy, hepatic dysfunction, craniosynostosis, microcephaly, and mental retardation. His sole source of nutrition is enteral formula through a tube. However, his insurer would not cover the cost of his enteral formula. His doctors had already appealed – twice – and lost. Juanita came to me two days before the deadline for filing an external appeal through the state Insurance Department.

Juanita's insurer had a novel, albeit deeply flawed argument. The state has a law that requires insurers to cover enteral nutrition for children under the age of 8 who suffer from an inherited metabolic disease.[10] The insurer said that this *required* them to deny coverage of enteral formula in all other cases – thoroughly ridiculous! Not only does this requirement not apply to a 14 year old, but it is a floor, not a ceiling, for coverage; of course, insurers can provide greater coverage if they so choose.

Preparing an external appeal in two days is easier said than done. Juanita did a lot of running around while I wrote. We gathered her son's medical records and showed that enteral feeding was his main source of nutrition, so he would die without it. More importantly in this case, we got the relevant portion of the Certificate of Coverage – the actual insurance policy – which said that enteral feeding is a covered benefit when: (i) ordered by a physician; (ii) if needed for the total caloric needs of the Member; (iii) because he or she has a gastrointestinal illness or injury preventing the normal absorption of benefits. Each prong of this test was met in this case. Thus, as we argued to the State, the policy actually supports coverage, not denial.

[10] Conn. Gen. Stat. § 38a-518c.

This may seem very clear-cut, but in the insurance world, nothing is clear-cut. The insurance company took the position that, even though enteral feeding is needed to maintain Juanita's son's growth and weight, it was not his *sole* source of nutrition; he was able to supplement the enteral feedings with small amounts of soft food. The insurance policy itself did not require that the tube feeding be the exclusive means of obtaining nutrition; it required only that it be needed for the patient's total caloric needs. In this case, tube feeding was needed because of "feeding difficulties, risk of aspiration and poor weight gain." Juanita's son had what are called jejuna atresia or malformation of a portion of the digestive tract. Even though he could eat a few bites of soft food such as pudding on occasion, there was no question that, based on his medical records, Juanita's son would die without enteral nutrition.

The State agreed. Juanita's son would have his enteral formula.

Tell me what the insurance company had to gain by fighting over food for a profoundly disabled boy?

Joanie, Robin, Jessica and Marni

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Joanie has inflammatory bowel disease. Her doctor prescribed a drug called Xifaxan. Xifaxan is FDA approved to treat "traveler's diarrhea." However, one of the theories behind inflammatory bowel disease is that it may be a reaction to bacterial overgrowth, which typically is treated with antibiotics.

Although bacterial overgrowth can be treated with any number of antibiotics, long-term antibiotic therapy has been known to cause patients to build up a tolerance to antibiotics so that, when they really need one, they can't find one strong enough to work. Xifaxan is different because it acts topically on the lining of the intestine, and most of it is not absorbed into the bloodstream, so patients who take it do not develop a tolerance to antibiotics. For this reason, Xifaxan is thought by some doctors to be a better long-term solution to bacterial overgrowth. I should know; I have been on Xifaxan since before it was FDA approved, when I had to get it from overseas, and it has done wonders for me.

Joanie worked in a medical office, so she had access to pharmaceutical samples, and took Xifaxan long enough so that she knew it was effective for her, too. The problem was that her insurer wouldn't cover it.

Robin also has inflammatory bowel disease. Her gastroenterologist is based at Mount Sinai Hospital, where Dr. Crohn worked when he gave Crohn's disease its name. Robin had limited access to samples, and was not working at the time her doctor prescribed Xifaxan, and her insurer denied coverage.

I did what I always do: I collected Joanie's and Robin's medical records, as well as medical journal articles reporting successful studies of

the use of Xifaxan to treat inflammatory bowel disease. Robin's doctor was particularly helpful in that he wrote a detailed letter explaining why Xifaxan and only Xifaxan would combat bacterial overgrowth without side-effects.

I lost both appeals on the ground that the FDA labeling limits the use of Xifaxan. This runs contrary to an FDA policy guidance issued in 1985, which states as follows:

> The appropriateness or the legality of prescribing approved drugs for uses not included in their official labeling is sometimes a cause of concern and confusion among practitioners. Under the Federal Food, Drug, and Cosmetic (FD&C) Act, a drug approved for marketing may be labeled, promoted, and advertised by the manufacturer only for those uses for which the drug's safety and effectiveness have been established and which the FDA has approved. These are commonly referred to as the "approved uses." This means that adequate and well-controlled clinical trials have documented these uses, and the results of the trials have been reviewed and approved by the FDA.
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> The FD&C Act does not, however, limit the manner in which a physician may use an approved drug. Once a product has been approved for marketing, a physician may prescribe it for uses or in treatment regimens or patient populations that are not included in approved labeling. Such "unapproved" or, more precisely, "unlabeled" uses may be appropriate and rational in certain circumstances, and may, in fact, reflect approaches to drug therapy that have been extensively reported in medical literature.
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> The term "unapproved uses" is, to some extent, misleading. It includes a variety of situations ranging from unstudied to thoroughly investigated drug uses. Valid new uses for drugs already on the market are often first discovered through serendipitous observations and therapeutic innovations, subsequently confirmed by well-planned and executed clinical investigations. Before such advances can be added to the approved labeling, however, data substantiating the effectiveness of a new use or regimen must be submitted by the manufacture to the FDA for evaluation. This may take time and, without the initiative of the drug manufacturer whose product is involved, may never occur. For that reason, accepted medical practice often includes drug use that is not reflected in approved drug labeling.

> With respect to its role in medical practice, the package insert is informational only. FDA tries to assure that prescription drug information in the package insert accurately and fully reflects the data on safety and effectiveness on which drug approval is based.

"Use of Approved Drugs for Unlabeled Indications," FDA Drug Bulletin, April 1982, Volume 12, Number 1, pages 4-5. Thus, the FDA itself has rejected the position that physicians should be restrained in prescribing off-label uses of drugs that are on the market, albeit for other uses.

Still, insurers adopted this rationale for denying coverage with the advent of Medicare Part D. The Medicare statute itself restricts Medicare from approving a drug for an off-label use (unless it is in one of three compendia), so legally, Medicare at least had a rationale for denying coverage of off-label uses, although this rationale is being challenged in a lawsuit brought by the Medicare Rights Center. However, commercial insurers have no such legitimizing rationale.

Regardless, insurers are denying coverage of off-label uses every day. In Joanie and Robin's cases, I pursued external appeals through the Connecticut and New York Insurance Departments, to external reviewers who upheld the denials of Xifaxan based on the FDA labeling.

In addition, at roughly the same time, two other patients came to me to appeal noncoverage decisions of Actiq, which is a pain medication FDA approved to treat cancer pain. The active ingredient in Actiq is Fentanyl, which is used every day for more purposes than I can list; it is used to treat pain from any number of sources, especially in the form of the widely used Duragesic patch, and it also is used as a "twilight" anesthesia, like you have for a colonoscopy. The only difference between Actiq and Fentanyl is the form it takes; Actiq is in the form of a lollypop so that it is absorbed sublingually and, thus, enters the bloodstream very quickly, bringing patients immediate relief. One patient, Jessica, had chronic pain of uncertain origin and was insured by UnitedHealthcare; the other, Marni, had pain due

to inflammatory bowel disease and fibromyalgia, and was in a Medicare Advantage Plan, a private HMO that administers the Medicare program.

Once again, both appeals were rejected. In the Medicare case, we went so far as a hearing before an Administrative Law Judge. Nobody would budge, even though I showed them the FDA policy guidance, as well as voluminous literature that proved conclusively that Actiq is, in fact, Fentanyl, and both Actiq and Fentanyl had been studied for use in treating noncancer pain.

This pattern continued. One insurer denied the use of 6-mercaptopurine, a chemotherapy drug, to treat Crohn's disease despite the use of immunomodulators like 6-MP in treating Crohn's for more than 25 years. Another insurer denied the use of growth hormones in a pediatric patient with inflammatory bowel disease despite his short stature and ample documentation tying inflammatory bowel disease to stunted growth.

The issue of off-label uses – uses of drugs for purposes other than what is reflected in the FDA-approved labeling – is centrally important in the current insurance climate. Medicare Part D handed insurers a new rationale, and if I cannot break through it, I would challenge anybody who thinks they can. Sure, there are exceptions here and there; not every insurer uses this rationale at all, and some insurers who use this rationale save it for new and expensive treatments. What I cannot figure out for the life of me is why this rationale is sustained in the face of the FDA's own 1982 policy guidance. If a doctor's experience tells her that a certain treatment may work, a departure from the FDA labeling should not be construed as justification for noncoverage. And yet, many insurers use the FDA labeling in precisely this way.

As this is being written, we are preparing a citizen's petition to the FDA to ask them to reconfirm their 1982 pronouncement. It certainly makes sense; the FDA does not regulate the practice of medicine. It can restrict

whether a drug manufacturer can market a drug off-label, but it cannot restrict what a doctor prescribes. And as it pointed out in 1982, when drugs are expected to benefit a relatively small number of people, drug manufacturers often do not invest the funds needed to compile sufficient studies to support FDA approval. Still, doctors can discover uses for drugs on their own, and there is no legitimate reason for an insurance company to refuse to allow them to do so.

Joanie stopped taking Xifaxan when the samples ran dry. Robin had to stop taking it immediately. Jessica has had to use oxycontin and oxycodone for pain instead of Actiq, and Marni spends $1500 a month out of her pocket for Actiq – an expense that requires that her husband work a second job simply to keep her pain in check. And I have nearly given up on filing insurance appeals when the denial is based on a narrow FDA approval, although I hope that our citizen's petition, if successful, will furnish me with new ammunition to try again.

How on earth can a patient mount an appeal on their own in a case like these? It simply is impossible; patients can't be expected to sit in a medical library and research studies on the off-label use of a particular drug, device, or procedure. And how can an insurer get away with using the FDA label as a basis for noncoverage in light of the FDA's own policy guidance? It's happening every day. It's wrong as a matter of law. And yet, it is allowed, even on independent review. This is a brick wall. It must be torn down.

Lola and Alana

Lola's son has very serious food allergies. Contact with peanuts, eggs, soy, or dairy could cost him his life. Mikey, who is 6 years old, was supposed to be in a "safe" classroom, in which all surfaces were disinfected every day, and all other students washed their hands whenever entering the room. But when Lola first called me, Mikey's "safe" classroom was one in which he sat on one side of the room all alone, while all the other children were set apart from him. He was segregated.

First, segregation without disinfecting and hand-washing doesn't guarantee that Mikey won't be contaminated. But even more, for a 6 year old to be segregated in this way felt like punishment, not like an accommodation. The teacher told the other students that they could only have certain snacks because Mikey is sick – the last thing Mikey wanted the other kids to know.

Mikey had a 504 plan that required that he have a paraprofessional with him at all times to ensure against contamination. However, the school was backing off of this promise, instead providing a paraprofessional "as needed." Toys and furniture in the classroom were not being washed, and children were being permitted to use hand sanitizer instead of washing hands with soap. Mikey's doctors said hand sanitizer does not decontaminate skin of all food residue.

One day, the teacher called Lola and said the class would be painting Easter eggs that day, and since Mikey couldn't be in contact with eggs, Lola had to come pick him up. Lola gladly would have provided plastic eggs and stickers for the whole class had she been told about this in advance. Instead, though, Mikey got excluded once again. It was at this point that Lola asked me to intervene and write the school principal. The principal reacted very

responsibly, requiring the teacher to review each week's lesson plans with the principal in advance to make sure that these issues were anticipated and dealt with properly.

Still, problems continued. Ultimately, we had another 504 meeting to discuss Mikey's needs. We were able to convince the school of the need to be very specific about the rules, and then to stick to them. Mikey's classroom would be "food free," although Lola was told pointedly that other parents complained about this. Students would wash their hands with soap after eating anything. Mikey would have his snack with the paraprofessional in the media center, while the other children would eat in the cafeteria – a distinction Lola was prepared to accept as a necessity. We reviewed the science curriculum to ensure that Mikey was okay with caterpillars and growing beans. Desks would be washed nightly. Social activities would not be focused on food; Mikey would have contact with his classmates in class, during recess, and during celebrations that would not be accompanied by food.

It's been a few months now since I last heard from Lola. Generally, that's a good sign. Hopefully, getting the 504 plan down on paper in minute detail helped Lola to ensure that Mikey is safe in school.

But this isn't just about Mikey. Kids with food allergies have a very tough time at school.

Alana has Celiac's disease, which is an intolerance to gluten. The primary symptom is diarrhea, but Celiac's is not a food allergy; it's an auto-immune disease, and can affect the joints, and even cognition. Gluten is very hard to avoid. Read a few labels. Gluten is not just in wheat flower; it is in condiments and canned goods – many places where you wouldn't expect it. Alana's bloodwork shows that her gluten levels are higher during the school year than in the summer, so her mom believes that she's getting gluten at school. She tried working with the head of the cafeteria services to ensure

that there were meals for Alana that were gluten free, but the school balked when they wanted to inquire of manufacturers about cross-contamination. So Alana has to bring lunch from home; she cannot enjoy the benefit of a hot lunch at school like all the other kids. And just getting the school to agree to have kids wash their hands and wipe down their desks after snacks has been a battle. Over the course of a year, the school has had conference calls with doctors and social workers, many meetings with the family, and, it seems, has done a fair amount of work internally, too.

Indeed, the dynamic of Alana's case is interesting because the school started out to be very helpful, and then shut down. Our best guess is that the school was upset that, after it had made what it thought were concerted efforts to ensure that Alana could eat a gluten-free school lunch, when the family pushed to ensure that manufacturers of the food were guarding against cross-contamination, and then decided to just send Alana to school with a lunch from home, the school just threw up its hands, feeling that its efforts were not appreciated. If you saw the letter the family drafted to send to the manufacturers, you would not be surprised; it was extraordinarily burdensome. However, other school districts simply purchase gluten-free lunches rather than trying to make their own, and that saves the school all that time and effort. And, even more, punishing a child because her family is fighting hard to ensure her health is just wrong.

Protecting kids from potentially life-threatening food allergies or intolerances is something schools have no grounds to avoid. But too many schools have to be dragged kicking and screaming; too many parents have to wage a battle of their own. Mikey's mom has thought about home schooling. But the answer to food allergies cannot be segregation, and it can't be punishment. Families and schools have to work together. After all, they share the common goal of protecting the child, don't they?

Elizabeth

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Elizabeth suffers from several psychiatric illnesses, most notably anxiety disorder. She was employed by the State University system on a contract basis, as a university assistant. At one point, she became hospitalized and her husband told her supervisor that he had no idea when she would be ready to return to work. She was immediately fired despite the fact that her husband had no authorization to speak for her, and the fact that he was wrong about her prognosis. She got out of the hospital and wanted to return to work, but there was no job for her.

I wrote to her supervisor alleging disability discrimination and a failure to provide reasonable accommodations. The school responded, through counsel, by offering her a different university assistant position. The first position she was offered did not materialize because Elizabeth did not have the requisite computer skills. However, a second position opened up and Elizabeth was offered the job.

In the meantime, Elizabeth had applied for Social Security disability and was awarded benefits in record time. However, she wanted to work if she could. Thus, when this position became available, Elizabeth wanted to accept the job while also ensuring that she would not lose her Social Security disability benefits. We had to carefully parse the return to work rules to make sure that Elizabeth was never over the income limit and would not lose her benefits. As most people know, you can earn upwards of $900 per month in any one month without losing benefits. However, most people don't know that, if you earn about $700 per month for any nine months in a rolling 60 month period, the Social Security Administration then requires that you attempt a return to work. The return to work rules are liberal in that, if you fail the return to work, you can get right back on benefits without reapplying and you don't lose your Medicare benefits during the return to

work attempt. But if you don't want to trigger the return to work rules, you have to be careful about how much you earn each month.

After much research and wrangling, Elizabeth started her new job, and for a few months, I did not hear from her at all. However, when the academic year ended, she was told that her contract would not be renewed because there was a hiring freeze. Elizabeth asserted that there were other, less senior university assistants whose contracts were being renewed. The school alleged that, although Elizabeth had more years as a university assistant, she did not have seniority in the particular job she was in, and there were others whose experience was far greater. The school would not budge, resting on the claim that the statewide hiring freeze prevented them from rehiring Elizabeth.

Elizabeth filed a complaint with the Commission on Human Rights and Opportunities. Her case is still pending.

Emilio

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Emilio and his wife came to the United States to escape a gang of warlords in Colombia. Emilio owned a farm there, and the warlords insisted that he either pay them most of his earnings or be kidnapped or murdered. He ran away instead.

While in the United States, Emilio's wife got pregnant with Rodrigo, the most gorgeous baby with black pools for eyes and curly black hair and a smile that is irresistible. Sadly, though, Rodrigo has been sick since the day he was born. I have known this family for almost four years, and he has had a feeding tube for longer than that. And you know when he is in pain because he screams and cries and makes you wish you were anywhere else.

Before Emilio found me, he hired an immigration attorney who filed an application for political asylum on his behalf. There were problems with this. First, the application was filed a month too late. Second, I'm told that political asylum claims are brought on behalf of people who are members of political groups, not individual farmers. I know little enough about immigration law so that the lawyer sounded to me as though he had a good grasp on the applicable law. Keep reading.

The family contacted us because they are desperate to stay in the United States so that Rodrigo can continue to get the medical care he needs, which he will not get in Colombia. As a United States citizen, Rodrigo is entitled to publicly funded health care, and he has gotten the best care available to children in the State of Connecticut. Emilio works as a dental assistant and earns enough money to pay for the family's other needs. He called us to see if there was anything we could do that his immigration attorney was not already doing to ensure that Rodrigo could continue to receive the care he needs.

We visited Rodrigo in the hospital several times and spoke with staff of various members of Congress, all of whom told us the same thing: let the immigration lawyer play out the case and hope he knows something I don't. Their chances were slim, at best.

For some time, there was the possibility of a guest worker program passing through Congress. President Bush was in favor of it, but it died in Congress. Meanwhile, the immigration case proceeded. The application for asylum was denied initially. Then it went to an Administrative Law Judge, who rejected the application. Then it went to the Board of Immigration Appeals. Denied again. But each step in the process took time, and time was what Emilio needed to get Rodrigo well enough so that he could go to Colombia without risking his life.

For awhile, I didn't hear anything, and on the theory that no news is good news, I didn't worry much. However, I never go to Connecticut Children's Medical Center without thinking about Rodrigo. He makes quite an impression.

About a month ago, I got a frantic call from Emilio. It seems his immigration attorney was convicted of forgery and now resides in a federal prison. A brief was due in the United States Court of Appeals for the Second Circuit in a matter of weeks, and Emilio had no lawyer.

I am a smart enough lawyer to know my limits. I know nothing about immigration law and was not about to try to fake it at the Second Circuit, where faking it is a recipe for disaster. So I got on the phone. I called Lawyers Without Borders, a nonprofit immigration group, and they gave me the name of an attorney who might take the case for free. Emilio already had paid the now imprisoned attorney everything he had, so money was very much an obstacle. Emilio went and met with this lawyer, who told him he had no case and should prepare to be sent "home" to Colombia. Emilio

refused to concede; Rodrigo needs to stay here to get the medical care he needs.

We tried other lawyers. Ultimately, Emilio used credit cards to get someone to file the brief. But my conversation with Senator Joseph Lieberman's immigration staffer was enough to tell me that the chances of success are extremely remote. She suggested that Emilio have someone start working on an application for prosecutorial discretion; even if Emilio lost his immigration appeal, he could apply to the federal prosecutor to exercise discretion and allow the family to stay in the United States due to Rodrigo's illness.

But there's a catch. Rodrigo may be sick enough to warrant keeping him – a citizen – in the United States with a parent, but one parent, not both. Emilio would not consider this option.

So we wait to hear from the Second Circuit. Most likely, the family will be deported to Colombia. Who knows what will happen to Rodrigo? What a cruel fate for a sick little boy to have to endure. To get the care he needs, he must be separated from at least one parent and possibly both of them. How cruel a system is ours?

The court case is not about Rodrigo; it's about his parents. But it ought to be about him. He is a citizen of the United States and he needs to be here with his parents to receive the care – and love – that he so desperately needs. Tragically, it appears that this will not happen.

Kathleen

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Kathleen lives in Beacon Falls, Connecticut. She has multiple sclerosis, lupus, a rare terminal blood disorder – and the list of diagnoses grows steadily. She lives alone, although two of her three children, her sister, and other relatives also live in Connecticut. She has two personal care assistants paid for by Medicaid.

Kathleen called us first because she had considerable debt in the form of student loans and believed that she was entitled to a discharge of those loans due to her disability. We met with Kathleen at her home, a double-wide trailer that is small but impeccably clean and orderly – except for the papers on her dining room table, which appeared to be in disarray, although I suspect that Kathleen had organized them in a way that made perfect sense to her.

I dove in with some trepidation. Kathleen already had the loan discharge form and had had her doctor fill out his section. There wasn't much for me to do, but I took the paperwork, got Kathleen to sign a release so that I could represent her, and left.

Since Kathleen had done most of the work, and the Financial Services Administration of the U.S. Department of Education had not yet gone into lock-down mode as they did during the credit crunch of 2008, getting the student loans discharged was a simple matter. We sent the forms with a cover letter certified mail and the loans were discharged. The only caveat was that Kathleen had to remain disabled for three years. Unfortunately, this was not a problem.

In the three years or so since then, Kathleen has become a regular Advocacy for Patients client. Her doctor told her she needed a new bed because her old one was not supporting her well enough, and her MS was flaring as a result. Kathleen called around to furniture stores until she found

one that provided furniture to people in great need. With a very small amount of advocacy from me, the new bed was hers – free.

This became a pattern with Kathleen. Although she is probably one of the sickest patients we've worked with, she doesn't like to give up control of matters that affect her directly. She wants direction and sometimes a little support, but for the most part, she knows the social services system at least as well as I do, if not better.

Recently, for example, the electric company decided it no longer would honor her arrangement to pay $90 per month every month because her arrearage was in the thousands of dollars. I did enough research to flesh out the problem. The electric company would not carry the arrearage any more, and to show her "good faith," which was necessary before she could enter into a new payment arrangement, she had to come up with a deposit of $450, which might as well have been $1 million to Kathleen. Our next call was going to be to the Office of Consumer Counsel, which represents consumers in disputes with utilities. However, Kathleen remembered that, when she originally set up her payment plan, she was assisted by a woman at the Department of Public Utility Control. Kathleen called her, the woman was still there, and the problem was resolved – I'm not exactly sure how, but it was resolved.

This happened over and over. Kathleen would call in a panic about something – the possibility of losing food stamps when her son was living with her; her periodic attempts to try to do some work, even without payment, just to feel some dignity; the effect of the fact that her trailer is in her niece's name. I would research and then Kathleen would take the matter out of my hands and figure it out on her own. Once I got her pointed in the right direction, Kathleen was able to navigate the system just fine.

Kathleen is a perfect example of what patients can do on their own if they so choose. Even when her hands are painful, she logs onto her

computer and finds new websites, calling me like a kid in a candy store when she finds one that might help not only her, but my other clients. Kathleen needs to feel useful, valuable. And so she has been. Despite the fact that she is one of our sickest clients, she is fiercely independent. That is important to her; she is too young, she says, to be reliant on others for everything. And so she accepts some direction, but never hands a matter over to us as so many less ill patients do. Kathleen is one of my heroes.

Every once in awhile, Kathleen calls and asks if she can read me something. One doesn't say no to Kathleen, so she does. Most often, it is a piece that is a blend of the religious with the inspirational. She gives these little essays to her doctors, she sends them to people she thinks are in need, and she reads some of them to me, especially when she writes about me, whom she sees as a sort of life-jacket.

Kathleen has romanticized our first meeting. In her memory, I am a mythic figure, appearing in her doorway as if I were an apparition, and from that first moment, she says, she knew we were going to be close friends. I believe I am one of Kathleen's closest friends, which makes me very sad, both because I am limited in terms of what time I can give her, and because I know she is very lonely.

Recently, Kathleen told me that her long-time neurologist told her that there is no more he can do for her, that her body systems were shutting down. She is not ready. She will get a second opinion. She talks to G-d: "I'm not ready yet. You can't have me yet." Then she adds, "Of course, He will take me when He is ready."

If Kathleen were well enough, she would be a professional patient navigator. Instead, she navigates the system for herself, largely with successful outcomes. Although she is one of the sickest patients we have worked with, she also is one of the most independent and productive.

Alicia

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Crohn's disease, like all chronic illnesses, can relapse or remit at any time. Patients do not get to choose when either one happens. Indeed, if they did, of course, they certainly would always choose remission. Instead, a relapse can occur regardless of prior commitments, responsibilities or scheduling conflicts – nearly always at the most inopportune times.

Take, for example, the story of 16 year-old Alicia and her mother, Claire. Alicia was approaching the end of the 2003-2004 school year when her mother first contacted me. At the time, Alicia was in danger of receiving no credit whatsoever for any of her classes because she had accumulated over fifty absences throughout the year. The majority of those absences, however, were the result of a Crohn's relapse. This Crohn's relapse struck Alicia during the height of her sophomore year in high school – from early March to early May. During that time, Alicia suffered nausea, severe cramping, extreme pain, and debilitating diarrhea, with as many as 8 to 15 occurrences per day. Obviously, these symptoms made it impossible for Alicia to get up and go to school. Her mom, Claire, made it a point to contact the school every day that Alicia was absent. She also made it a point to regularly contact the school guidance counselor, the resource room teacher and the school nurse to provide health updates and/or to ask questions about missed work. Likewise, Claire consistently furnished the school with notes from Alicia's doctor.

Even though she was sick, Alicia made every effort to keep up with her work, but received very little help from the school. This is where the problem was. Tutoring was not offered until mid-April, after Alicia already had accumulated a significant amount of absences, and even then, the first tutor did not work out. By the time a second tutor was assigned, Alicia had started going back to school. This meant that she would often go from a full

day of school, to the town hall until 9:00 pm to do make-up work with her tutor, and then arrive home to do even more work in order to keep up with her ongoing assignments – a Herculean effort even for healthy high school teenager, let alone one in the midst of a relapsing chronic illness.

Alicia diligently completed every make-up assignment and exam that she was given for each of her six classes. For example, she completed all of the work for her English, Geometry and Interior Design classes, but had trouble completing the work for her Human Development class simply because her teacher could not clearly tell her what needed to be made-up. Similarly, a Human Development exam that she requested to take in the Resource Room – an option available to her as a special education student for issues unrelated to her Crohn's disease – never was provided to her Resource Room teacher, leaving Alicia unable to take it. Even worse, Alicia's Civics teacher refused to accept any of the make-up work that Alicia took the time to complete, because he considered it late. As for her last class, Biology, Alicia acknowledged the possibility of having to re-take it because of the difficulty of making up in-class labs.

In order to appreciate the difficult task Alicia took on by attempting to catch-up and complete all of her work, it is important to note the obstacles facing Alicia in addition to recovering from her Crohn's relapse. First, Alicia was a special education student because of a learning disability she needed help with. Second, she had to deal with a lot of different side effects from the many medications she was on to keep her Crohn's in remission. One of these side effects included a direct effect on her immune system, making her more susceptible to catching illnesses. This is why Alicia missed a few days of school even after coming back from her prolonged absence.

Instead of taking into account all of the efforts Alicia made to complete her assignments, and instead of evaluating Alicia's degree progress

on a class-by-class basis, the school principal simply issued a blanket statement in a letter dated June 10 saying that Alicia would not receive any credit for the school year because of her excessive amount of absences. This letter was just as bewildering to Alicia and Claire as the school's decision to cut off Alicia's tutoring, without explanation a few weeks earlier.

The principal's decision failed to take several facts into account. First, it failed to consider the two half-year classes for which Alicia already was given credit. Next, it failed to acknowledge the state and federal laws that made the decision illegal. Finally, it failed to recognize that it violated the school's very own policies on how to deal with chronically ill students. These policies included: requirements that the school make arrangements for appropriate instructions at sites other than the school itself in cases of extended absences for acceptable reasons; requirements that the school provide students with long-term chronic diseases with an alternative education program; and requirements that the school convene a Long-Term Chronic Disease Programming Team within ten school days of learning of a student's chronic illness in order to devise a program for the student. Furthermore, the school's policies clearly stated that, "[s]tudents not in school or class for a legitimate reason . . . will not be charged with absences," and, "[s]tudents will be allowed to make up any work missed due to an absence." The school violated every single one of these policies in Alicia's situation, even the one providing for at-home instruction as it was discontinued without explanation.

Even under the threat of losing credit for an entire year's worth of work, Alicia took all of her final exams. She then went on to spend the entire summer unsure of whether she would be a junior in the fall, or a repeating sophomore who would be graduating high school a year behind her friends. The school did not confirm that her credits were restored for all of her classes, except Biology, until one week before the start of the new school

year. It certainly was good news, but good news that could have and should have reached Claire and Alicia much sooner.

Chronic illnesses do not wait to relapse during scheduled school vacations. Alicia's relapse occurred in the middle of the school year, causing her to be absent and fall behind. As a student with a chronic illness, she is not alone. Alicia's was my very first school case upon starting Advocacy for Patients, and since then, I have encountered countless questions and problems arising for chronically ill students at the elementary-, middle-, high-, undergraduate-, and even graduate-school levels. These students face unique obstacles as they seek to complete their education and manage their chronic diseases. They should not, however, have to face obstacles from their teachers and schools. At times, they may require more help and accommodation from their teachers and schools, but they should not be viewed as troublesome students with troublesome parents. There is no place for an adversarial relationship in the school setting. Chronically ill students are no less capable of success than students without chronic illnesses and schools should be helping to ensure that success.

Martine

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Martine is a thirty-three year old writer. Roughly four months ago, she began to experience symptoms that were very unusual for her; it started with urinary incontinence, and then she developed some weakness on one side, and then she started to have vision problems, balance problems – her ability to make her body do what she wanted it to do began to slip away. Her symptoms progressed quickly, and she was as afraid as she should have been.

She went to see the chief neurologist at a very well-respected medical center. She had every test known to humankind, and they all came back normal. However, because she was seeing such an experienced clinician, he was able to diagnose her problem as transverse myelitis.

Transverse myelitis is a chronic, demyelinating disease like multiple sclerosis. It strips the nerves of their myelin sheath, so the nerves in the body simply may no longer work. It progresses quickly, and if not treated quickly, the functional deficits that accrue become permanent.

Martine's doctor started her on IV Solu-Medrol followed by oral prednisone, or steroids. However, the steroids did not reverse her symptoms or stop the progression of her disease. Then her doctor tried plasmapheresis, or plasma exchange – sort of like a transfusion or, even more so, like dialysis – which also did not reverse her symptoms or stop the progression of her disease. Finally, her doctor tried IVIg, intravenous immunoglobulin, the primary substance that healthy people have enough of, that makes the immune system work right. When Martine had plasmapheresis followed by IVIg, she had about ten days of relief – but that was the only relief she had, so IVIg appeared to be the right missing ingredient.

However, Martine's insurer, Aetna, wouldn't cover IVIg for transverse myelitis. They took the position that it is experimental.

I got Martine's case from a wonderful woman named Kris McFalls, the patient advocate for *IG Living*, a magazine that is dedicated to addressing immune deficiencies. Kris asked me if I would be willing to do battle for Martine. I have handled several insurance appeals for coverage of IVIg for relapsing-remitting multiple sclerosis, so I thought I probably could learn enough about transverse myelitis to handle this appeal, and I did.

I did a lot of research and found quite a few medical journal articles documenting the beneficial use of IVIg to treat transverse myelitis. Martine's mother happens to have a job that provides her with access to a medical library, so she was able to obtain the full text of these articles, which made my life much easier than it otherwise would have been. I also gathered Martine's medical records. I read and read, and then I wrote, and submitted the appeal just before Christmas.

Immediately after New Year's, I got an inquiry from Martine – how long did I think the appeal would take. I said roughly thirty days. I get that question a lot, so I didn't think twice about it. Then I got an email from Martine's mother saying that Martine wasn't doing well, and that she was considering taking out a home equity line of credit to pay for Martine's IVIg. And then I learned that Martine was going blind. A writer, going blind. At 33 years of age, walking with a cane. If four months of ineffective treatment allowed the disease to progress this rapidly, then what would happen if treatment were delayed further? Now, I knew I had someone's life in my hands.

And so I called Aetna to see if they could expedite the appeal. They already had sent the very large file to an outside neurologist for review. They checked with the outside reviewer and he said he would need some time – at least the upcoming week-end – to complete his review. Aetna was

earnest in trying to help us to expedite the process, and asked the reviewer to do the best he could. We all resigned ourselves to waiting until the following Monday for an answer.

So when the phone rang on Friday afternoon and caller ID told me it was a call from Aetna, my heart immediately began to pound. We won. The reviewer agreed that, since the IV Solu-Medrol and plasmapheresis didn't work, IVIg was a reasonable next step.

Martine was overjoyed, as was her mom. They both lavished generous praise on me, which was really quite touching. As for me, I was relieved more than anything else; having someone's life in one's hands is stressful, to say the least.

One might think the story would end there, as it should. However, after her first round of IVIg treatments, Martine's employer put her on an involuntary, unpaid 90-day leave of absence. Whatever joy Matine felt at winning her appeal was wiped away all too soon. Since she is a writer, she may well be able to perform the essential functions of her job from home, possibly with the help of adaptive technology such as a larger computer monitor and/or a voice activated computer, all of which would be reasonable accommodations under the Americans with Disabilities Act. As I write this, Martine is thinking about whether she wants to fight this, and whether to start the process of applying for Social Security disability if it turns out that she really is unable to work in the future.

With chronic illness, just when you think you've conquered a major obstacle, another obstacle appears.

Maria

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Maria's case may be the most difficult case I've handled. Maria, who speaks no English (and I speak no Spanish), needed surgery on her throat. The doctors in the United States who saw her said that she would have to have a tracheotomy and would not be able to speak normally ever again. However, there was a doctor in Medallin, Colombia who said that he could do the surgery without affecting Maria's vocal cords.

Step one was to get Maria's insurance to be willing to pay a doctor and hospital in Medallin, Colombia. We had to get a detailed estimate from the hospital in Colombia – and again, I speak no Spanish, so I was communicating through third parties much of the time. The Colombian hospital knew nothing of CPT codes, the system by which American insurers decide whether to cover a procedure and how much to pay. But we managed to get a detailed list of procedures, treatments and supplies from the hospital, and the insurance company then produced an estimate of what it would pay. Based on that, the insurance company and the hospital agreed; we had a deal.

I'm making this sound far less complex than it was. There were several players – the hospital, the surgeon, the surgeon's billing intermediary in the United States, the insurance company, the Union representative who helped advocate with the insurance company, and the insurance company's billing agent – it was quite a cast of characters. And it took coordinating all of them to make this happen. My communication with Maria was through her young daughter, who speaks perfect English and Spanish, but who did not understand the nature of the transaction.

And then there was the matter of paying for plane tickets and having to make a last-minute run to New York to pick up plane tickets for a different date than that for which tickets initially were purchased.

But Maria made it to Columbia. She had the surgery. She stayed as long as she could, but her return plane ticket would expire six months from the date of purchase. So at the end of six months, Maria came back to Connecticut.

Within a week, she was in the University of Connecticut Health Center with a tracheotomy. All of that work and the result she was trying to avoid was the result that occurred in the end.

The story doesn't end there, though. The Colombian hospital billed the insurance company. Because the hospital was out of network, the insurance company mailed the check to Maria. Because Maria ended up with a tracheotomy, her husband refused to send the check to the hospital in Colombia. I got frantic calls from Colombia insisting that I get them their money. I went to Maria's home and met with her and her husband. They refused to budge. I counseled them strenuously to understand that the money was not theirs; they could not legally hold it or spend it. They insisted that the surgeon in Colombia fix Maria's medical problem if he wanted to get paid. They didn't have plane fare to send Maria back to Colombia, and the insurance company surely wasn't going to pay twice. In the end, I had to inform the hospital that I no longer could represent Maria because she refused to follow my advice and send the insurance check to the hospital. I still get a call or email from the hospital every so often.

I'm not sure what the lessons of this case are. Maria wanted to have the surgery performed by the best in the world, and supposedly she did. She wanted her American insurance company to pay for it, and we made it happen despite the fact that this is nearly unheard of. In the end, though, the surgery failed, and the resulting financial mess could not be resolved by agreement. Even with extraordinary efforts and cooperative doctors and insurers, there will be failures of care.

Cleve, Kyle, George and Others

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Did you know that you can't serve in the military if you have a chronic illness? Or that you could be fired from your job as a policeman, firefighter, security guard, or federal employee if you have a chronic illness that in any way affects your job, even if reasonable accommodations would allow you to perform all of the essential functions of your position? I sure didn't.

My first clue came when Cleve contacted me because he was graduating from law school and wanted to become a military attorney, but he was told that he would not be allowed to do so because he has inflammatory bowel disease. I was outraged; what possible justification could there be for barring people from enlisting in the military because they are sick?

We fought hard, even contacting the patient's Congressional representatives. The Army was like a brick wall; we got no explanation – just a big NO.

Then, Senator Hillary Clinton finally got involved. She was on the Armed Services Committee, so the Army had to give her the explanation that they would not give us. Their rationale: All enlistees must be vaccinated, and due to the fact that Cleve's medication suppresses his immune system, the vaccinations would not be safe. Once we were given a rational explanation, there was nothing more we could do as a matter of law. But realistically, wouldn't it be pretty easy to station a military lawyer in a place where live vaccines are not needed?

Over the years, we have seen this sort of practice – although mostly without such a rational basis – in many contexts. For example, Kyle was a security guard. He has Crohn's disease and, thus, needs access to a bathroom. When he was posted at an indoor location, he was fine. When he

was posted as part of a pair, he was fine. But when he was posted alone, especially outside, he had to leave his post to use a bathroom, and kept getting disciplined as a result. We sought reasonable accommodation of his disability; all he needed was to be near a bathroom or stationed with a partner and he could do the job. Instead, he got fired, and we negotiated a severance agreement rather than a plan of accommodation. The employer preferred to spend money rather than retain a chronically ill employee.

George enlisted in the Air Force because his life's ambition was to fly fighter jets. He had dreamed of it his entire life. He wasn't sick before he enlisted. When he got sick and had to be hospitalized during basic training, he was shocked to learn that, inside his well-toned body, there was a ticking time bomb, ulcerative colitis. The Air Force deemed him unfit to serve. We researched Air Force regulations to try to find a way to compel the Air Force to retain him, or at least give him an honorable discharge so that he could obtain VA health benefits. He appealed all the way up the chain of command. He obtained a second opinion. Matters only got worse; his second colonoscopy showed that his disease was more widespread than initially thought. George shed many tears as I did my best to keep his spirits up through long phone conversations. But in the end, his dream was shattered. He would never fly an Air Force jet, no matter how successful his medical treatment was.

Richard was in Naval ROTC when he was diagnosed with Crohn's disease. Although his disease was controlled quickly after his diagnosis and a brief medical leave, when he attempted to return, he was ejected from the program. We requested a waiver of the medical exclusion, but our request was denied. It didn't matter that Richard could do everything after his diagnosis that he could do before his diagnosis. The military simply wouldn't have a midshipman with Crohn's disease.

Barry is a corrections officer. He has ulcerative colitis and underwent surgery to create an ostomy (a small piece of bowel is pulled through the abdominal wall through which waste is discharged into a bag or appliance). When his surgeon cleared him to go back to work, he had to pass a physical with a Department of Corrections physician. The physician – who clearly knows nothing about ostomies – said that he could not perform the essential functions of his job because, according to her, Barry could not restrain an inmate, would need to have a special bullet-proof vest (despite the fact that Barry had never needed to use a bullet-proof vest in his 14 years with the Department), and would require many other special accommodations, none of which had any basis in medical fact. We appealed to the Department, the Governor, and ultimately, the head of employee health services. Ultimately, our argument that this was nothing short of ignorant bias about ostomies carried the day, and Barry was allowed to return to work. But it was quite a battle.

Similarly, Ed works in a maximum security prison. He sought reasonable accommodation in the form of transfer to a post where he could be near a bathroom. Ed stated that there were many such options. However, his employer fought us every step of the way. Ultimately, the employer relented, but without legal assistance, Ed most likely would have lost his job.

John is a firefighter who asked for reasonable accommodation in the form of not working the overnight shift because his physician felt that doing so was compromising his health. Lou is a police officer who has made the same request. In both cases, the employers argued that they could not make exceptions to the order of seniority due to the union contract. In John's case, we were able to demonstrate that federal law – the Americans with Disabilities Act – trumps any contract. Lou's case is still pending.

Steve applied for a job as a police officer and was denied due to his Crohn's disease. The Department claimed that he could not perform the essential functions of the job due to his illness. By the time he found me, it was too late to appeal the denial.

Tom is a police officer who has Crohn's disease. Every time he takes time off – even if it has nothing to do with his Crohn's disease – his supervisor asks questions and makes him feel as though his job is on the line. So far, he has not been disciplined, but he is afraid for his job every day.

Pete is a police officer who was not allowed to apply for an open promotion because he used too many sick days in the previous three years, even though most of his absences were excused by a doctor's note.

Nancy is a firefighter who has an ostomy and was threatened with job termination, again based on the uneducated belief that an ostomate could not perform the job.

The problem extends beyond the military and law enforcement, to all government positions. Serena was excluded from serving in the Peace Corps because she could not be vaccinated for yellow fever. Adam applied for a job in the State Department and was hired provisionally, but then was rejected after failing the physical examination due to his Crohn's disease.

I catalogue these many instances to demonstrate how widespread the attitude is among military, law enforcement, and the federal government in general that they have the right to discriminate based on chronic illness. Some of the time, when I, a lawyer, have gotten involved, we have obtained good outcomes, at least in law enforcement. However, there does not appear to be even the slightest fissure in position of the U.S. Military, or in the underlying attitude.

Here we are, in the midst of a war in Iraq and a war in Afghanistan. Over the past few years, we have heard repeatedly that our military is stretched to the breaking point and people are being deployed for very long

time periods, for repeated tours of duty. And in that context, the military won't accept willing and able-bodied enlistees simply because they have a chronic illness, even if it is in remission and has been for a considerable length of time?

Whether it be the military or law enforcement or the federal government, disability discrimination should be illegal. The chronically ill should not be barred from serving their country.

Louise

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Louise had metastatic colon cancer. Her ex-husband is a partner in a very large and prestigious law firm in Connecticut, and her father was on the state Supreme Court. She had lived a privileged life until she was divorced and, ultimately, became ill. Despite the fact that she did not work during the marriage, at the time she came to me, she was not receiving alimony, and was trying to work as a title searcher when her health permitted her to do so.

Louise came to me with piles of medical debt related to her cancer. One large hospital bill stemmed from charges related to a post-operative infection Louise contracted while in the hospital. We asked the hospital to write off that bill entirely; Louise had complained and complained about fevers and discomfort for days and days after her surgery, but it was not until she had an abscess that the hospital and its physicians took her seriously. The hospital billed $56,000 for this occurrence.

We applied for charity care at the hospital – nonprofit hospitals like this one receive funding for uncompensated care provided to low-income patients. The hospital did give Louise a substantial discount on her outstanding hospital bill, and Louise's other medical creditors agreed to payment plans. Still, she owed a lot of money, all related to her illness.

We talked about bankruptcy. Louise really wanted to pay her bills, if only she could pay them off over time, while she worked. However, the sicker Louise got, the harder it was for her to work. She was receiving a small Social Security benefit – she only qualified for Supplemental Security Income (SSI) rather than the larger Social Security Disability Income (SSDI) because she had not worked enough in the preceding years – but she was barely able to pay her rent, and in some months, she was unable to comply with the payment plan to which she had agreed. She had exceeded her

credit limit on her existing credit cards. I wrote letter after letter, especially when Louise's cancer spread to her brain, trying to keep the creditors at bay. Despite the fact that they knew she was dying and was broke, the creditors were relentless.

At one point, her ex-husband gave her $5,000 to pay off some of the hospital bill so that the hospital would continue to treat her. However, Louise was desperate to pay her rent and utilities, and used the money for these sorts of necessities rather than paying off the hospital bill.

Some creditors hired lawyers. The fact that she had no income other than her Social Security check did not deter them. I wrote letters documenting each spread of the cancer, from liver to lung to brain. Still, they pursued collection. The number of letters I wrote on Louise's behalf are too numerous to count, just trying to keep her out of bankruptcy court.

And then came the word from Louise's daughter that Louise had died. Although this came as no surprise, it was so sad to think of Louise, having fallen from the prosperity in which she was raised, and in which she lived during her marriage, to living in a small rental in a rural town owing thousands of dollars, with few friends and relatives providing her with any support at the end of her days.

Her daughter told me she left behind two full shopping bags full of medical bills. In the end, Louise had stopped forwarding them to me. Ultimately, death came more easily to her than bankruptcy court.

Cindy

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Certain illnesses are particularly difficult to prove by objective evidence, from chronic fatigue syndrome to Lyme disease to multiple chemical sensitivity to depression to chronic pain. Although we have won several disability insurance appeals involving these conditions, the story I want to tell is one that we lost because it illustrates the problem so well.

Cindy has chronic fatigue syndrome (CFS). She worked as a discharge planning coordinator at a hospital, which required her to gather information on the patient and family; contact five agencies as needed for placements; make additional referrals to placements as necessary; provide feedback to social workers; meet with social workers to monitor and prioritize discharge plan for each patient; insure all paperwork and documentation needed to accompany patients is available; identify problems that delay discharge; oversee final discharge arrangements; participate in team meetings; maintain updated information on facilities; assist with departmental reports regarding discharge planning; maintain ambulance log; provide feedback on ambulance performance; submit statistical reports; perform activities in compliance with JCAHO and department standards; attend and participate in in-service meetings and trainings; demonstrate and maintain current knowledge and skill. In addition, the job description stated that Cindy "is regularly required to stand, walk, and talk and/or hear. The employee is also required to sit. The noise level in the work environment is usually moderate."

According to the Centers for Disease Control, CFS is characterized by "profound, debilitating fatigue "that results in substantial reduction in occupational . . . activities." The fatigue is "not improved by rest, may be worsened by physical or mental activities" and is accompanied by characteristic symptoms such as problems with memory and concentration,

muscle and joint pain, headaches, and, of course, fatigue. "The illness is marked by a dramatic decline in activity level and stamina. People with CFS perform at a significantly lower level of activity than they were capable of prior to the onset of the illness."

The CDC states that "there are no diagnostic tests or laboratory markers for CFS. . . ." Diagnosing CFS is a challenge for a number of reasons. Patients must experience reductions in their previous ability to perform at least one aspect of daily life, such as work, in order to receive this diagnosis. Patients suffer fatigue that is not relieved by rest and lasts longer than six months. The CDC advises doctors to consider CFS if there is unexplained, persistent fatigue that is not due to ongoing exertion, is not substantially relieved by rest, is of new onset, and results in a significant reduction of previous levels of activity AND four or more of the following are present for six months or more:

- Impaired memory or concentration;
- Postexertional malaise;
- Extreme, prolonged exhaustion and exacerbation of symptoms following physical or mental exertion;
- Unrefreshing sleep;
- Muscle pain;
- Multijoint pain without swelling or redness;
- Headaches of a new type or severity;
- Sore throat; and/or
- Tender cervical or axillary lymph nodes.

CFS is a "diagnosis of exclusion," meaning it's a diagnosis you are given after all other possibilities are ruled out. Thus, one would expect to see many negative test results as a diagnostician was ruling out other diagnoses.

According to the CDC, "all CFS patients are functionally impaired. While symptom severity varies from patient to patient, CDC studies show that CFS can be as disabling as multiple sclerosis, lupus, rheumatoid arthritis, heart disease, end-stage renal disease, chronic obstructive

pulmonary disease (COPD) and similar chronic conditions." The most common co-morbidity is fibromyalgia.

Thus, CFS is difficult to diagnose; is diagnosed based on the presence of primarily subjective symptoms; and is extremely debilitating.

Cindy has all of the usual symptoms of CFS. She is extraordinarily fatigued. She cannot concentrate or perform more than one task at a time. She is overwhelmed easily. She has myalgias along with the fatigue. She becomes stiff after sitting or standing. She is sensitive to noise. She drives only occasionally. She has memory problems. She even finds it difficult to get dressed in the mornings. In addition, she suffers from fibromyalgia, which is the most common co-morbidity with CFS. Also, she has a history of hypothyroidism, endometriosis, a Rathke's cleft cyst, and sinus problems.

The insurance company's physician was looking for objective evidence, where the CDC says that none exists. Thus, evaluation and assessment by an expert immunologist is as reliable a diagnostic tool as exists today. Cindy's doctor – who is a leading expert in CFS – noted that Cindy experiences profound exhaustion that lasts up to 24 hours and is not relieved by rest. Cindy tested positive for Epstein Barr Virus (EBV), which is commonly associated with CFS. She also had low carnitine levels, which also is associated with CFS, and low amino acid levels, which contribute to her fatigue. We submitted a SPECT scan of the brain that showed decreased blood flow to the brain, which contributes to Cindy's cognitive deficits. Thus, there were some objective findings supporting Cindy's complaints.

Cindy's primary care physician stated that she is unable to work due to CFS, marked by fatigue that does not resolve with rest, muscle pain, joint pain, sleep disturbance, post-exertion malaise lasting more than 24 hours, morning stiffness, headaches, and impaired memory. He noted the active EBV results, and also that she suffers from fibromyalgia.

According to the immunologist, Cindy also suffers from growth hormone deficiency and paradoxical parasympathetic response. She stated that "[Cindy's] autonomic nervous system response demonstrates 'paradoxical parasympathetic response' which means that one branch of her nervous system is overcompensating and that [t]here is an imbalance between the two branches of this system which leads to further symptoms, such as palpitations, night sweats and sleep disturbances," further contributing to Cindy's fatigue. An endocrinologist was treating Cindy's growth hormone deficiency by prescribing a supplement.

Over time, the immunologist noted other symptoms that impact on Cindy's ability to perform the functions of her own occupation. For example, she stated that Cindy cannot talk on the phone or read for more than 10 minutes at a time due to her confusability and cognitive problems. Lab results showed diminished natural killer cell function, indicating an abnormal immune response.

A neuropsychological evaluation confirmed all of these conclusions. Attention and concentration were significantly impaired. Perceptual-motor functioning was reduced due to disorganization and slow performance. Memory was poor. The "ability to shift cognitive set and benefit from feedback on tasks of mental flexibility was also significantly impaired." Speed of reading was slow. Significant anxiety and depression were indicated.

Cindy's diagnosis of fibromyalgia was confirmed clinically, and x-rays of her neck showed some degree of osteoarthritis. A rheumatologist stated that she also had arthritis in her hand. An MRI of the pelvis showed moderate degenerative disc disease at L4-5. Thus, there were objective findings that supported Cindy's complaints of joint pain.

In short, there seemed to me to be no question that Cindy's impairments were objectively verifiable.

The insurer disagreed. They discounted almost all of the objective evidence as "unimpressive." While they acknowledged that there were abnormalities, they simply did not believe that the abnormalities were bad enough. And they concluded that fatigue alone is not disabling, apparently unconvinced even by the CDC.

The only good news about this case is that Cindy also applied for Social Security disability and was granted benefits. Although the insurance policy defined "disability" according to Cindy's own occupation, and Social Security requires a showing that the claimant cannot perform ANY occupation, Social Security found Cindy to be disabled under its more stringent criteria. Go figure.

Wendy

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Wendy has Crohn's disease and fibromyalgia. She is in constant, severe pain. The only medication that has controlled her pain in the past is Actiq, which is a pain medication (fentanyl citrate) in the form of a lollipop, which allows it to be absorbed into the system quickly. Actiq is FDA approved for treating cancer pain, but not any other type of pain. Thus, many insurers refuse to cover it for treating non-cancer pain.

Wendy's insurer won't cover Actiq, so she uses as few as she can and makes them last as long as she can. She buys what she can afford, but it is very expensive, so she never has enough to control her pain at all times.

So Wendy got desperate.

Wendy wrote two bad checks to buy Actiq. She knew they were bad checks – she wrote them on closed accounts – and she knew what she was doing was wrong. She'd never violated the law before. But she was in agony and she had no money. So she did what she felt she had to do.

And now, Wendy is facing two felony charges and prison time. Because her insurance doesn't cover the one medication that brings her some relief.

Russell

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Russell was a very sick little boy – a baby in fact. By the time he was 14 months old, Russell already had suffered an enormous amount from what his doctors believed to be Crohn's disease.

His parents, Beth and Karl, watched their baby suffer since the time he was only 2 months old. At that time, they brought him to one of the best children's hospitals in the country because he had bloody stools, or hematochezia. That turned out to be only the beginning. For the next several months, they watched Russell suffer from uncontrollable gastrointestinal bleeding, life-threatening anemia, intake disorder, growth failure, and a failure to thrive. Then, after spending months in and out of the hospital, trying and failing a laundry list of medications – including dietary restrictions on Beth in order to keep dairy out of her breast milk – they found out that the next, best option available, Leukine therapy, would not be covered by their insurance company.

The initial denial letter Beth and Karl received stated that their Benefit Plan's criteria for medical necessity was not met because Russell's, "diagnosis of colitis [did] not meet criteria for approval." This, however, was an overly simplistic assessment of Russell's condition. Although he was too young to be affirmatively diagnosed with Crohn's disease, his doctors were certain that he had some type of inflammatory bowel disease, and because areas beyond his colon were affected – the duodenum, for example – they also believed that his symptoms more closely resembled Crohn's than ulcerative colitis. As a result, Beth and Karl decided to appeal the decision.

The denial letter specifically, and strangely, stated that the appeal, or letter asking for "reconsideration," had to come from the member, not from the doctor. Because this did not seem right to Beth, she called her insurance company and asked – after being on hold for a half hour – if she should send

a letter from Russell's doctor. She was told no – the letter had to be from her. She also was not told that she could submit any additional information, such as a letter from the doctor or any other materials. As a result, the appeal was denied the day after it was sent.

The second denial letter stated again that the request was denied because Russell didn't meet the "criteria for approval," whatever they were. It further stated that the request was reviewed by an Independent Physician Review Board that confirmed the denial. That decision, however, was made without any medical records or information from Russell's doctor. The only information this Review Board had was the drug requested and Russell's age. With a severely ill baby on their hands, this outraged both Beth and Karl.

Beth, naturally, called the insurance company to complain about the clearly erroneous information she was given and to demand that she be able to submit the additional information that she should have been permitted to include at the outset. After several phone calls with various people at the insurance company that only led to a confusing mess of conflicting information, Beth and Karl – with my help – decided to proceed to the next appeal level. Because Karl is a federal employee, the next appeal was to the United States Office of Policy and Management.

The appeal focused not only on the fact that Russell most likely had Crohn's disease, and not simply colitis, but also focused on the reason for why the off-label use of Leukine was warranted – indeed, medically necessary. Russell already had tried a number of medications that provided little to no alleviation of his symptoms before turning to Leukine. For example, routine drugs and treatments for Crohn's disease, such as 6-MP, mesalamine, and a solely elemental diet, were tried but caused allergic reactions. This not only ruled these treatments out, but also ruled out similar drugs, such as Azulfidine and mercaptopurine. Intravenous and tube

feedings also were tried, but failed to provide any lasting relief. Steroid therapy did not help, and Russell's doctors were uncomfortable with using methotrexate in such a young child.

The reality was – and it remains true today – that every drug except for Prednisone and Remicade is considered to be an off-label use for a child Russell's age. Prednisone, a steroid, already was determined to be ineffective, and Remicade carried with it a lot of unknown risks; Remicade's risks – including infection and lymphoma – were considered too costly to warrant its use in Russell's case due to his young age. Likewise, other alternatives, such as methotrexate, cyclosporine, thalidomide, Humira, Cimzia, Tysabri and other such drugs all carried with them far greater risk than Leukine.

Even more convincing than Russell's history with tried and failed drug treatments and the risks associated with other non-Leukine drug options, was the fact that Russell's doctors also chose Leukine because of its success in a clinical trial conducted at their hospital a few years earlier. In that trial, Leukine was shown to generate a good clinical response in children with Crohn's, resulting in prolonged remission.

Before Beth and Karl received the good news that we won the appeal and that their insurance company would pay for Russell's Leukine treatments, they had decided to pay for the treatments themselves – taking the best pediatric gastroenterologists in the world at their word: it was the next, best option for their son. Indeed, they saw Russell, for the first time in his short life, stabilize and improve a little on the treatment. He was able to stay out of the hospital while he was on the medication. But without the insurance company's coverage of the treatment going forward, that kind of progress would have halted once Beth and Karl ran out of money.

The appeal we submitted contained Russell's medical records and medical journal articles on the use of Leukine for IBD. Thankfully, the Office

of Policy Management granted our request for approval of the use of Leukine in this case. Although they did not state much in the way of reasoning, the end result was what we cared about – now, Russell has a shot at getting better! Indeed, he already is.

Trent

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Trent already suffered from a spinal cord injury and severe neurological problems, requiring the daily help of a personal care assistant ("PCA"). Trent already was poor – he was on Medicaid and lived in a modest apartment.

Then, his teeth starting falling out, and everything got much worse.

Beginning in September 2005, Trent's teeth did not just fall out; they broke off, often at the gum line, and left razor sharp edges. One minute he would be talking and the next, he would pause to cough up blood and a tooth that just broke off. He woke up in the mornings with blood on his pillow, in constant pain, and no longer could eat solid foods. Over the course of just one month, Trent lost over 40 pounds and was so weak that he would sleep for 30 hours at a time. This was advanced periodontal disease at its ugliest.

Clearly, Trent needed a dentist. Yet, he could not find one who would accept Medicaid in time to respond to his rapidly deteriorating condition. Provided with a list of dentists by his social worker from the Department of Social Services ("DSS"), Trent called every dentist he could to take care of his teeth. Every one of them turned him away – some because they no longer accepted Medicaid patients and some because their Medicaid patient quotas were filled. Trent and his PCA then started looking on their own. They checked the phone book and used every search engine they could think of on the Internet to find a dentist. Trent even faxed letters to dentists throughout his state, pleading for help, but to no avail.

During this time, Trent tried to get treatment at his State University's Health Center, as DSS told him to do. Instead of treating his emergent condition, however, they told Trent that there were no appointments available for another four months and that they could only pull out one tooth per visit if he chose to walk-in each day.

Trent became so desperate that he sold his car in order to see a private dentist and to have his most painful teeth pulled. With puss coming out of his mouth, the dentist gave Trent an antibiotic and told him that all of his teeth needed to come out immediately. If he waited too long to have them taken out, he was at risk for further infection and even death.

This was the predicament: Trent needed emergency dental care, but could not find a dentist enrolled in the Medicaid program ready or willing to provide that care. During this time, Trent was in constant communication with DSS and his social worker, trying to find a solution to his urgent situation. Finally, someone from DSS told him that he could go out of network to take care of his emergency. Taking the DSS worker at his word, Trent scheduled the appointment and finally had the work done that he so desperately needed. He is alive today because of it, but that is not the end of the story. He also is bankrupt.

DSS refused to pay for Trent's dental care, claiming that he went to a dentist who was not enrolled in the Medicaid program and that he was treated for non-emergency care. Before I got involved, DSS did not even want to provide Trent with his right to a hearing on the decision of whether to pay the dentist's bill. Even after the hearing, DSS ignored the testimony of Trent and his PCA, and even the pictures Trent took of his mouth during his month-long ordeal, and denied Trent's appeal of their non-coverage decision. To add insult to injury, DSS not only claimed that Trent did not require emergency care, but that he could have chosen from a variety different treatment options. However, Trent had no way of knowing about these "other treatment options" because he never was able to see a Medicaid enrolled dentist. The only reason Trent went to the private dentist was because no DSS-approved dentist would see him in the first place.

As a result, Trent was left with an overwhelming medical bill that he could not pay. Just a little over one year after the whole nightmare started, Trent had to declare bankruptcy.

Sally

Sally did not like to draw attention to herself. As a petite, 11 year-old student trying to successfully navigate her way through middle school, she especially did not like to focus attention on her medical needs. But that doesn't mean she didn't have any.

Sally has ulcerative colitis, a type of inflammatory bowel disease. This chronic disease causes a number of symptoms, but at the time, the most salient one for Sally was her lack of appetite and resulting weight loss. With her lunch time scheduled for 1:00 pm during the school day, Sally found that she got hungry in the middle of the morning. Because she already was having trouble meeting her caloric intake, it was imperative – if not medically necessary – for Sally to be allowed to snack when she was hungry.

In order to satisfy this need as discretely as possible, Sally used to "sneak" a snack from her locker in between classes. Once her psychologist/family therapist from the Children's Hospital of Philadelphia became aware of this, however, she encouraged Sally's family to talk with the school. Aware that students had merely three minutes to move between classes and get the materials they needed from their lockers, Sally's therapist thought there must be a better solution.

Taking her advice, Sally's parents requested a meeting and had the following language added to their daughter's 504 plan: "Snack in designated area in morning." Originally, Sally's parents were told this meant that Sally could have a snack in class, with the understanding that she would be discrete. After one complaint from another student about Sally eating during class, however, the school revoked the original plan. Instead, the school's new plan was this: Sally could leave one class 15 minutes early, go to the principal's office to eat, and then arrive at the next class 5 minutes

late. This plan meant that Sally missed 20 minutes of class per day – over an hour per week.

To make matters more complicated, Sally's ulcerative colitis was coupled with, "anxiety which ha[d] resulted in focusing and organizational difficulties in the classroom setting and at home." Sally struggled academically and needed all the extra help she could get. As a result, the "solution" that Sally could miss up to 20 minutes of class per day in order to eat her snack compromised her efforts to succeed academically. An 11 year-old was being forced to choose between her medical needs and her academic needs.

Fortunately, this story has a happy ending. Due to my intervention, the school eventually agreed to allow Sally to eat a snack whenever and wherever she needed, except for the gym, where food was not allowed. One of Sally's teachers even changed his policy to allow every student to break for a snack during class time, making Sally one of the more popular kids in the class!

The sad part, however, is that none of this happened until I got involved. Requests for this very solution by Sally's parents, doctor and family therapist were rejected. It was not until the school received the letter from me, with my legal letterhead, that they responded.

Should kids really need a lawyer to ensure that they receive cost-neutral accommodations in school?

Theresa

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Theresa has a cluster of auto-immune diseases including rheumatoid arthritis, Sjogren's syndrome, and connective tissue disease. She has applied for Social Security disability, but she is having problems documenting her illnesses and treatments because she has no health insurance and, thus, cannot see a doctor. We tried to find her free clinics, but they will not let her see a specialist, and the internists at the clinics don't feel that they can treat her complex needs.

No money means no insurance means no health care means no Social Security which means no money. A vicious cycle, indeed.

Victor, Mary and Others

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We get a lot of inquiries from patients who believe they have been discriminated against at work or school. This is the story of a few of these cases.

On October 23, 2006, I received an email from Victor stating the following:

> I'm a 49 yr old decorated service connected disabled (colitis) veteran whose symptoms increased to the point that I required retraining through the v.a. voc rehab program. While in my summer clinical rotation in the rad program, my symptoms increased to the point that I was coming in late and missing days. This required that I work with the disabilities office to get accommodations for my symptoms. As soon as the paperwork was signed the negative reviews came in. I have been discriminated against for my age, the color of my wife's skin, my disability, and allegedly being a whistleblower for the programs illegal treatment of students.

In other words, Victor is a veteran whose colitis led to a disability rating through the Department of Veterans' Affairs ("the VA"). Through the VA's vocational rehabilitation program, he enrolled in a program to be trained as an x-ray technician. He sought and obtained accommodations because he found that, due to his colitis, he was late or absent on a relatively frequent basis, and believes that he was retaliated against because of that, as well as for other reasons. What his initial email didn't say, but which I subsequently learned, is that he ultimately was expelled from the program for allegedly poor performance.

Victor's main allegation is that the clinical coordinators gave him inadequate clinical placements in which to complete the clinical portion of the program in retaliation for his requesting accommodations. He was told that he could simply take a grade of Incomplete, but felt that this was unfair because other students' needs were being met. However, no matter what he

did, his schedule prevented him from completing the "competencies" that were required. When Victor asked for an alteration to his schedule, his request was denied, although other students were being similarly accommodated.

When Victor complained, he started to receive bad reviews for patient care. However, he claims that his skills did not deteriorate, and his prior reviews were excellent. When he asked to come to work to obtain his "competencies" during spring break, this request was not granted until the last minute, whereas other students' similar requests were granted ahead of time. He had several meetings with supervisors, and was written up for being disrespectful and disruptive. He claims that he was threatened with expulsion if he did not sign these write-ups. Victor kept a diary once he began to feel that he was being treated discriminatorily, and he had documented incident after incident in which he was blamed for substandard work that he contends was not his fault for various reasons – primarily, the lack of consistent instruction and supervision. Victor contends that his negative reviews at the end of a semester were more evidence of the lack of adequate training and supervision rather than an accurate reflection of his performance.

As often is the case when a patient believes he or she has been wronged, Victor took on this case and this cause as one that he was championing not only on his own behalf, but on behalf of all of the other disabled students who would follow him. A professor accused "someone" of "calling the sheriff," and Victor was convinced that referred to his "whistleblowing" by reporting his treatment to the powers that be. He was accused of tape recording sessions that were not allowed to be recorded shortly after that. And on and on and on. All of these bits of injustice, for Victor, amounted to proof that the system was corrupt, and it was up to him to correct it.

I don't know – I never will – whether Victor and others like him are right. Because Advocacy for Patients does not litigate, when we are contacted by a patient who already has commenced litigation or is determined to do so, we coach the patient, but we do not formally undertake to represent them. If the patient was willing to settle, we might try to negotiate a fair resolution, but we have found that, once a patient has dedicated himself to a cause like Victor has, it's very difficult to talk them into letting it go.

Victor filed a complaint of discrimination with the Commission on Human Rights and Opportunities. He also filed several complaints with the Freedom of Information Commission to get all of his records, and to uncover what he hoped would be evidence of his mistreatment. He has rejected all settlement offers, and is attempting to litigate the case on his own, with occasional coaching from me.

I tell this story not only because Victor may well be right – he may have been treated punitively due to his request for accommodations and his persistent insistence in securing his rights – but also because he is one of many patients with whom we work for a period of years as they try to litigate cases that no attorney will take because the cases either are lacking in merit or evidence, or the financial stake may not be great enough so that an attorney could afford to litigate the case for one-third of what it ultimately is worth. What I struggle with in these cases is the amount of energy these patients are spending on things that have gone by, that have to be left behind if the patient is to move on.

For example, in another case, Mary was fired from her job, allegedly due to her disability. She was a professional employee of a pharmaceutical company. When she became ill, she took disability, but ultimately, when there was no sign of her returning to work, she was fired. Legally, once an employee uses up her leave under the Family and Medical Leave Act, if

attendance is an "essential function" of the job, and attendance is impossible, the employee can be fired even if the reason for their absence is illness. Still, Mary was determined to sue her employer, which is located a couple of states away from where she now lives. Because she was so ill, her filing was not ready until the day the statute of limitations – the time allowed for filing suit – would expire. She tried to drive herself to the courthouse and called me from the side of the road out of desperation. I tried to explain to her that her suit had no legal merit, but she was determined, despite a high fever, to make it to the courthouse before it closed. She did, and got the court's date-stamp on her copy of the papers. However, because of defects in the filing, it was all returned and the case was never docketed. The statute of limitations ran. I thought Mary understood that this was the end.

A year later, Mary is still trying to figure out a way to get her case before some sort of tribunal – if not a court, then and administrative agency – anybody!

Lisa is another veteran. She believes she was the victim of medical malpractice at the Veteran's Home. She sued and lost. Because her care was delivered by the Veterans' Administration, now she has brought her claim before the VA in an administrative proceeding.

Christine's husband was a veteran, and she, too, believes that he was mistreated at the Veteran's Home, and that this was only one instance of negligence by the VA. Indeed, she believes this is why her husband died. She has spoken with several attorneys, and everyone told her the same thing – she doesn't have a case. She and I corresponded in a very long series of emails, and I thought she actually had agreed to let the matter go. But then I heard back from her a couple of weeks later with what she hoped would be a different angle from which she could pursue her cause, perhaps not on behalf of herself, but on behalf of all veterans.

I could go on. I don't know if this sort of pattern exists among the public at large, or whether patients with chronic illnesses are more likely to dig their heels in and refuse to move on. Surely, patients with chronic illnesses have more interaction with medical professionals than the general public, so the incidence of malpractice – or at least bad outcomes – among them probably is higher. And because chronic illnesses can be disabling, the chronically ill are more likely to feel that they were discriminated against due to disability. So it follows, then, that among the chronically ill are many people with many beefs against doctors, employers, schools. But I don't know if they are more likely to pursue these claims to the bitter end, or if this is simply a human trait, the search for justice, for right and wrong.

What I do know is that this fixation on the past – especially when all means of redress have been exhausted – is unhealthy. Litigation is unhealthy. That is one reason why Advocacy for Patients does not litigate. Although I help these patients as best I can, I also spend a lot of time trying to convince them to let go of the past and move forward. Perhaps I am wrong to judge at all, but when I see a patient like Mary using her last bit of strength to drive three or four hours to file a lawsuit that never had any chance of success, I can't help but feel that there has to be a better way.

Tina was a federal government employee. She was fired due to lateness and absenteeism caused by ulcerative colitis. She retained a lawyer and sued for discrimination and lost. What has her hung up is that the judge, in his decision against her, cited testimony inaccurately, as shown by reference to the trial transcript. Her lawyer promised to handle the appeal for free, but then sent her a bill for over $30,000, which she paid, only later complaining to him that he'd broken his promise. Tina's biggest complaint is that the judge didn't listen, that the transcript shows that he got the testimony wrong, that her lawyer didn't keep his promise. I think she might

be able to get past her horrible experience if she felt that she was treated fairly, even if she still lost.

Perhaps if these patients felt listened to, respected, and understood, they would not be in fight mode 24/7 and could move on with their lives.

Conclusion

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These stories represent only a fraction of the cases we've worked on at Advocacy for Patients with Chronic Illness, Inc. Choosing which stories to tell has been difficult because all of them are so compelling. What you have read here is a representative sample. Each was selected because it represents a group of our cases; we have not simply selected the most dramatic cases. Still, in my view, they are dramatic, indeed.

But the important point is this: If half the people in the United States have at least one chronic health condition, then half the people in the United States are coping with these sorts of very difficult, complex issues every single day, most of them alone, without resources or guidance. Every day, I think about the patients who don't know I'm here, and I wonder how they manage. The fact is that many of them don't.

The need to educate and assist patients to navigate the system on their own is clear. Those, like Kathleen, who are able to participate in their own care management with just a little direction, will save the taxpayers many thousands of dollars over their lifetimes because they are more compliant with doctor's orders, leading to improved health outcomes and lower costs.

It also is clear that chronic disease management has to go beyond the doors to the medical office if we are serious about helping the chronically ill learn to navigate the system. As the foregoing stories show, chronic illness affects work, school, and social life. Patients need the tools to manage their disease as a whole, not just some subset of it.

In the end, it seems to me that, if we are a compassionate society, we cannot refuse to offer help to the chronically ill. Chronic illness is a large, heavy, complicated cross to bear. Providing economically efficient assistance to the chronically ill not only will save us health care dollars

because it will result in improved health outcomes, but it also simply is the right thing to do.

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