I still remember getting a call from the young mother of a patient of mine named Leo. She was concerned about a bad cough and shoulder pain. Leo was about 8 years old.

I remember thinking that a cough with shoulder pain seemed unusual. So I asked her to bring him to the Emergency Department for an x-ray.

I remember hearing that Leo’s x-ray showed a strange chest mass – a mass that we quickly determined was a tumor that required emergency radiation to avoid crushing his trachea and stopping his respirations.

I remember his mother crying, wondering whether her young son would live.

She paused long enough to ask me whether it would be possible for the Boston Housing Authority to find the family a new apartment, so Leo did not have to sleep in bed with his brother while he was undergoing chemotherapy.

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In Leo’s case, his tumor was pathological, with the cure in a textbook. His housing status was administrative, with the eventual answer in an appeal to a government agency.

But from the point of view of Leo and his family … the medical and legal were two sides of the same illness. Often the more acute the medical need, the more essential the legal support.

As participants in the Medical-Legal Partnership, you live at this corner, bringing both the tools of good medicine and good law to the assistance of patients across the country.

It is not a quiet corner.

There are the asthmatic children who need help ridding their environments of allergens … families who need to qualify for benefits so they do not have to choose between food and medicine for their kids … patients who must appeal a denial to qualify for the treatment he or she needs to live.
The web of medical and legal stressors can be overwhelming to the patient as much as to her caregivers. The good news is that untangling this web can be empowering to both.

You are the untanglers.

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And I am your biggest fan. I believe I trained in pediatrics in one of the first, if not the first, medical-legal partnership clinics in Boston in the late 1990s. My fellow resident was Dr. Megan Sandel … and our chief of pediatrics Dr. Barry Zuckerman. I remember when Ellen Lawton was hired.

Around this time, I took care of a young girl with wheezing on the wards of Children’s Hospital. Her mother looked exhausted, and I offered an empathic comment. She explained her other daughter was in the intensive care unit, and a third daughter was at home starting to cough.

Was there a pet at home? I asked. No, said the mother.

A cold going around? Negative.

What an amazing coincidence! I remarked.

Well, the mom said, I wonder if it has anything to do with the fact that we have no heat and our spaceheater is smoking and smells real funny.

I called over to Boston Medical Center and spoke to one of the lawyers.

She sent me the Housing Code. I called the landlord, and gave taxi fare to the mom to go home and meet with the repairman for the heat. She later called me to the hospital room to tell me it was all fixed.

This was one of the highlights of my pediatric training … and you all do this every day.

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This is a special time for the medical-legal partnership. As the Partnership has grown to more than 200 sites, you have taught many about the importance of working across professional boundaries, focusing on the needs of patients, including: doctors in training, medical administrators, allied health professionals, and legislators.

You are developing credibility within your institutions and communities.
And you are creating for yourselves new opportunities to advocate on behalf of patients and change policy.

You should take advantage of these opportunities.

Both through individual cases and through systematic analysis, the Medical-Legal Partnership should identify areas for improvement in social policy … and then fight for them.

Every so often, a clinical case reveals a legal issue that requires a policy change for resolution. This is the policy equivalent of finding a medical case that reveals a new insight into the pathogenesis of disease.

**The policy issue can be administrative.** I remember working the overnight shift as a resident at Boston Medical Center and admitting three children – all of whom had psychiatric illness and were waiting for admission to a psychiatric hospital. But none had room. So we called the children “boarders,” and put them up for days without real treatment in the pediatric unit.

We advocated for them … calling, calling, calling. But we also asked the question: what was the policy failure that kept these children from receiving the care they need?

I traced the funding for these children through multiple sources. It turned out the medical side of Medicaid was not paying for their admission because they had a psychiatric diagnosis … and the psychiatric carve-out company was not paying because the children were in an unapproved location.

Actually, nobody was paying the hospital. The system’s clinical and financial incentives were misaligned … to put it mildly. We teamed up with parents to explain this analysis to legislators and the public. I remember a father who told a TV interviewer something like, “When your child is suicidal, you want help right then. Right then. Not in three days. Not in five days. Right then.”

The advocacy led to a number of policy changes and now Massachusetts has some of the most innovative services for children with mental illness in the country.

**The policy issue can be commercial.** Several years later, I was working for Congressman Henry Waxman and I received a call from a friend of mine from college and medical school. A dermatologist from Philadelphia. He had consulted on an infant with a bad rash, swelling, and irritability. He had diagnosed kwashiorkor, protein-calorie malnutrition. In Philadelphia. And then another child presented with the same problem.
He saved their lives with this diagnosis. But what had caused the problem? It turned out the parents were feeding these infants rice milk, thinking it was a hypoallergenic alternative to real milk. In fact, rice milk has virtually no protein, and these children were starving.

Bad parenting? When my friend took a look at the marketing of the drinks, he found that they promised to be complete nutrition and alternatives to milk. One was called Rice Dream.

He wrote an article for a medical journal that he titled “Rice Nightmare.” He reviewed more than a dozen cases of serious injuries, and death, from kwashiorkor associated with rice-based beverages.

He could have dropped it there. After all, his patients were better and he had a publication to his name. But he didn’t want other children to suffer the same fate. So he called the local paper, and the Inquirer wrote a story. Still not satisfied, he called me, a friend who worked for a great member of Congress.

Congressman Waxman wrote each of the companies with his concern, as well as the FDA. Nearly all immediately changed their packaging to advise that children under 5 should not consume the products without discussing first with a doctor.

**The policy issue can be regulatory.** When I served as the Commissioner of Health in Baltimore, I became aware that several deaths of children had been partially attributed by the coroner to the overuse of over-the-counter cough and cold preparations.

I knew from my training that these preparations had never been proven to be effective, and could cause significant safety problems. I worked with the chiefs of pediatrics in the city to issue a statement to parents urging them not to use these products for children under age 6.

Someone then called us and asked, “If you can get all the pediatric experts to advise not to use these, why are they on the market?”

I assigned a medical student to figure out the answer to that question. I gave her the numbers of a couple of lawyers.

She found out that the products’ history stretched back nearly 30 years, and that they had never been found by FDA to be safe and effective. We petitioned the agency to pull these products from the market to protect children. Right before an advisory committee heard our petition, the product manufacturers pulled products for children
under age 2 from the market. Soon after the committee meeting, companies pulled products for children under age 4.

Recently, data from poison control centers and emergency departments has shown a tremendous decline in complications from these medications for young children, reflecting thousands of fewer adverse events each year.

Policy issues are local, state, and federal. They involve rulemaking, court cases, or legislation. They are as wide and varied as clinical conditions. You often have to work to understand them well. But solving a policy issue is often a great moment in prevention. It is a public health achievement.

If the Medical-Legal Partnership does not make this a priority, who will?

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At any point in time, using your advocacy for individual patients to identify important policy issues would be important. Today, with major transitions in the health care and social service systems underway, it is critical.

The implementation of the Affordable Care Act provides tremendous opportunities for policy change and advocacy to benefit patients.

Many new provisions in the law strengthen insurance coverage – we have to hold companies to these provisions, so that the few who do not abide by the rules are not taking advantage of the many who do.

Other provisions provide new access to care. Helping patients navigate this new system of health benefit exchanges will identify a host of policy issues. As the Secretary of Health of a state keen on implementing this law to the benefit of our residents, I am eager for feedback about what is going right and what is going wrong. Strong partnerships between those designing the system and those who know how it is working will be critical for its success.

And today, the day after the anniversary of the signing of the Affordable Care Act, we cannot ignore the threats to its successful implementation. There are still some in our country who seem to believe that the solution to health care costs is to drop people from coverage. I suppose their idea is out of the system, out of the cost column. But of course, it doesn’t really work that way. Keeping someone out of the doctor’s office where he or she can get a prescription for blood pressure medicine … is the very definition of penny wise and pound foolish. Someone has to pay for the ambulance ride, the neurological evaluation, and the chronic care for a devastating stroke.
Nobody may hear of the family’s heartache, but if you live in a state seeking to move backwards … you can help them to tell their story.

Yesterday, I spoke after Congressman Elijah Cummings at a forum at a community college on the Affordable Care Act. Congressman Cummings described that he arrived hours early to the House floor for the vote one year ago, so he could get a front row seat. He said that as he waited, he said he hoped that he would not have a heart attack before being able to cast a vote on such a historic piece of legislation.

His message yesterday was simple: We cannot go back.

In a few hours, I will watch as our Governor Martin O’Malley, senior U.S. Senator Barbara Mikulski, and Attorney General Douglas Gansler celebrate the one-year anniversary of the Affordable Care Act with Secretary of Health and Human Services Kathleen Sebelius.

The location will be a consumer assistance center, where advocates take calls from Maryland residents and help them with their insurance challenges. These centers received critical infusions of support through the Affordable Care Act.

Maryland’s center is located just a few blocks from here, at the corner of medicine and the law. I mean, over there on St. Paul Street.

* * *

My patient Leo and his family did get assigned to a much safer apartment. Megan and I worked with some great people at the Boston Housing Authority to make sure of that.

We also asked how we can help the many other patients whose health was affected by their housing. We launched an effort using a new technology tool – I believe it was called electronic mail? – to obtain hundreds of stories from clinicians. We reviewed the medical literature and wrote a report. We consulted with attorneys.

And then we called a press conference.

It was with Dr. Barry Zuckerman’s encouragement, and Megan made it happen. We found ourselves, in between our hospital shifts, in a recently lead-abated home in Boston with U.S. Senator John Kerry and a bunch of news cameras.

With us were Leo, wearing a surgical mask, and his mother. When she had heard what we were doing, she eagerly wanted to participate.
We used this momentum to link with national housing advocacy groups fighting for an expansion of the Section 8 program and with the federal Department of Housing and Urban Development, which has carried the torch on healthy housing programs in the years since.

We were novices. You are professionals. I urge you, as you consider the direction today for the Medical-Legal Partnership, to keep in mind the importance of effective policy work to improving the lives and health of hundreds if not thousands of people.

Thank you for inviting me today, and I look forward to your questions.

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