Advocating for Change in Medical Legislation

Advocacy is becoming an increasingly important role for physicians, and there is extraordinary value to becoming effective advocates on behalf of our patients. Until recently, advocacy was not a formal part of medical school or residency curricula. The American Academy of Pediatrics (AAP) has published an extensive overview of advocacy for the pediatrician. This online guide breaks down legislative reform efforts into individual, community, state, and federal levels. We focus here on state and federal legislative advocacy, the practice of taking a position, and initiating actions in a legislative arena so as to deliberately influence policy choices. Health law can have a profound impact on a physician's practice of medicine, and there is a general call for physicians to become advocates for changes in public policy. However, there is little in standard medical journals outlining how medical personnel may specifically advocate for changes in laws that affect our daily professional lives. We describe here a recent effort to change the law in Rhode Island regarding HIV testing in pregnancy and use that effort as a launching pad for broader discussions of how involvement in legislative change can be an important and rewarding process for hospitalists.

OUR PATIENT’S STORY

In 2006, a 4-week-old term infant presented to our hospital with a chief complaint of fever and rash. On the second hospital day, after an accidental needle stick, the child’s HIV status was reported as positive. The child had a prolonged hospitalization with gradual improvement. Two salient facts emerged from this case. First, the mother had been offered HIV testing while she was pregnant but had refused. Second, had she accepted testing, there is a strong likelihood that her infant would not have acquired the disease. Limitations in current state law allowed the infection to progress and motivated us to try change the law.

DOING YOUR HOMEWORK

Embarking on the path of legislative advocacy, it is imperative to review existing legislation. Examples often exist in other states. Understanding previous efforts at local or national levels is critical to defining your argument and understanding the best route forward. Countless resources are available to assist with this research. Organizations that specialize in the area of interest, medical societies who engage in advocacy such as the local AAP chapter, and even universities are an excellent place to start.

The vertical transmission of HIV was first noted in 1982, and in 1985 the Centers for Disease Control and Prevention (CDC) first recommended counseling of selected “at-risk” pregnant women. Since then, 3 categories of state laws around testing...
have arisen: “opt-in,” “opt-out,” and mandated newborn screening (Table 1). These categories are general, and there is still variation within each approach regarding counseling, consent, and other finer points.7

NEW YORK STATE AS AN EXAMPLE
The state of New York was an early leader in law reform regarding peripartum HIV testing. In 1996, New York developed an opt-in approach whereby health regulations mandated HIV screening be offered to all pregnant women. In 1997, after conducting surveillance of routine newborn screening tests for HIV, they enacted the “comprehensive newborn testing program.” Positive newborn screens were now reported to the child’s pediatrician, regardless of parental consent. Because screening for the disease was already being conducted, this law simply enabled dissemination of available information. Soon it became apparent that treatment of HIV in the immediate postnatal period could dramatically reduce transmission rates, even if the mother was not treated.8 This finding encouraged New York to alter their law in 1999 to create mandatory newborn screening immediately after birth. Disease transmission rates were reduced by approximately two-thirds.9

To further improve testing rates, in 2001 the CDC published a national guideline to switch to opt-out testing.10–12 Opt-out meant that HIV tests were performed with other routine prenatal tests, without specific written consent. The opt-out approach has been mandated by a handful of states, with variable success but with universally superior results to the opt-in approach. Figure 1 presents rates of prenatal HIV testing in various states.13–18 Beyond the opt-in versus opt-out categories, a handful of states have replicated New York’s efforts in newborn screening. One unexpected consequence of rapid testing of newborns was a dramatic upswing in testing rates of mothers during pregnancy. Among states that currently mandate newborn testing, maternal testing rates are now generally >95% (Fig 1). At the time of the initiation of our legal reform effort, Rhode Island mandated opt-in testing for all individuals, and although testing was mandated in pregnant women, testing rates were only 53%. Based, in part, on the successful efforts in New York and other states, we decided to pursue both opt-out testing and a mandatory newborn screening program for Rhode Island.

MAKING THE CASE
Evidence-based physicians may be swayed by large randomized clinical trials, but legislators are often more interested in a patient’s story. A story makes the issue real in a way that fact sheets and statistics alone do not and captures the attention of community leaders, elected officials, the media, and the general public. Evidence and references need to be readily available; however, humanizing the issue elicits emotional investment from legislators and ensures their political investment to facilitate change.

Medical research review can be conducted through traditional means, but research must also be done on legal precedent and fiscal implications. Legal research can be conducted by searching state or national governmental Web sites. Simple online searches can uncover newsworthy events and even advocacy programs that have already vetted and summarized relevant information.

A surprising amount of fiscal information can be found through medical databases such as PubMed by using appropriate search terms. Cost of procedures, medications, and laboratory tests are routinely available from hospital administrations and laboratories. The fiscal responsibility of new bills must also be addressed. In our index case, the care of the patient in the first few months of life exceeded $500,000. It was very powerful to compare the cost of treating 1 patient versus the cost of an enzyme-linked immunosorbent assay test while the mother was pregnant ($10). The lifetime-incurred cost of only a handful of patients contracting HIV could cover the $120,000 annual cost for effectively screening the entire state.19,20

KNOWING YOUR OPPOSITION
Understanding who will oppose you on a legal reform effort and anticipating their arguments are critical issues when speaking with legislators. Opponents will most certainly be engaged with legislators, often with the help of paid lobbyists. Researching

### TABLE 1 Definitions of Types of Laws and/or Health Regulations Regarding Prenatal HIV Testing

<table>
<thead>
<tr>
<th>Regulation</th>
<th>Definition</th>
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<tbody>
<tr>
<td>Opt-in</td>
<td>Universal testing for HIV is mandated but is not included in routine prenatal testing.</td>
</tr>
<tr>
<td>Opt-out</td>
<td>Universal testing for HIV is mandated and is to be included in routine prenatal testing. As such, written consent for testing is not required. Patients are tested by default.</td>
</tr>
<tr>
<td>Newborn testing</td>
<td>Testing of newborns immediately after birth is mandated in infants whose mothers do not have a documented test result. Consent for testing is not required.</td>
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organized opposition through online publications is useful. For example, we found the following statement on a Web site sponsored by the American Civil Liberties Union: “AZT treatment itself can be highly toxic. Given the risk it poses, it would hardly be unreasonable for a pregnant woman with HIV to decide not to undertake the regimen, whether because of considerations about her own health or the unknown long-term effects on the baby.”21 We were able to clarify that antiretroviral therapy is safe in pregnancy and in children.22,23 Anticipation of this argument and finding data to back up dis- sention were key.

Meeting with anticipated opponents before any legislative hearings may also be helpful. Acceptable compromises may be made that limit oppositional testimony and dramatically enhance the likelihood of success. Allies can be found in unlikely places, and opponents are not always “enemies.” In a later advocacy effort regarding sexual edu- cation in public schools, support by the American Civil Liberties Union was critical to our success.24

BUILDING SUPPORT

Building a team of effective backers is vital to the survival of a bill. In our case, several local and national organizations deeply involved with HIV were recruited. Supporters are easily identified through networking and simple online searches. Professional organizations such as the AAP can be critical in securing backing; however, it is useful to keep in mind that not all medical organizations support the same agenda. For those organiza- tions that do not have a strong opinion as to the particular issue at hand, it is worthwhile pursuing their support. The backing of multiple organiza- tions lends significant power to the issue and to your efforts.

Another key source of backing is the local Department of Health (DOH). Having their support is likely to sway legislative votes because once the bill is passed, the DOH will be responsible for drafting regulations that further define the bill. Getting to know a key member of the DOH will go a long way toward making the bill a success. They may provide constructive feedback.

FIGURE 1 Rates of prenatal HIV testing in women in states with opt-in, opt-out, and newborn screening mandates. *Data from before 1999. †Data from select counties. ‡Data from after 1999. Data are from references 13–18.
on a proposed bill or even assist with drafting legislation. Even when, politically, they are not able to openly endorse a bill, they will be valuable advisors and often mediators in negotiations with opponents.

HOW A BILL BECOMES LAW
To understand where advocacy may be most effective, health advocates must be aware of basic rules that guide the movement of legislation through the system. Bills generally must follow a certain prescribed course, with 4 critical points that pose distinct opportunities for involvement by the physician advocate.

Choosing a Sponsor and Drafting a Bill
Advocates should seek a House or Senate member whom they have reason to believe is supportive of the issue, often through a personal connection to the cause. Preparation for the initial meeting with a sponsor or their staff is vital. A written summary, references, and contact information should be provided. It should be clear whom the physician represents. Without demonstration that the physician represents larger organizations, the legislation is unlikely to sponsor the bill. Frequently, advocates who propose the legislation are asked to comment on or even write specific sections for the legislation. Advocates should seek assistance from other members of their coalition around a cause, particularly public health organizations and/or professional organizations that often can help research and draft a legislative proposal.

While drafting a law, it is important to remember that the preamble to the law (“whereas clause[s]”) is an extremely powerful tool. Opposition groups often fixate on elements of the law itself but will not comment on the initial paragraph describing the intent of the law. The intent of the law is paramount because most health-related laws are further clarified by DOH regulations after passage and, as such, clear text in the preamble will allow the DOH to craft very specific regulations “in the spirit of the law.” Careful attention to the preamble will save hours of negotiations later.

Testifying Before a Committee
Some basic strategies are very helpful in testifying before a committee. Physicians should be mindful of specific state rules and/or restrictions regarding providing testimony. Most politically active medical organizations can help you identify these issues. Physicians new at testifying may be concerned about getting caught up in technicalities, although this is rarely the case. Effective testimony is simple, straightforward, and from the heart. Testimony as a representative of an organization is more effective and may be as simple as getting a letter of support from the leader(s) of the organization. It is vital to make clear at the outset which organizations an advocate represents during testimony.

Generally, testimony is limited to 5 minutes. Sometimes, questions and answers will extend that time. A brief presentation should be prepared, and clear and concise written handouts with references and contact information should be provided, with sufficient copies for all committee members.

Testimony should be polite and to-the-point: provide a summary of the most important issues and relay the personal story. Prolonged opportunities to testify and clarify points are often provided when testimony is delivered with good eye contact and arouses the interest of the committee without straying too far from the logical confines of the argument.

Having a quick-minded, debate-oriented physician prepared to provide testimony late in the hearing will allow you to effectively rebut counterarguments brought up by the opposition. This strategy was critical to passage of our bill.

Finally, it is important to note that the timing of hearings can change at any moment. Working with a lobbyist or having a contact in the legislature can help alert the physician of a last-minute change in schedule.

Passing the Bill on the Chamber Floor
When a given committee recommends passage, the bill is placed on the calendar for floor debate, beginning in the chamber of the bill’s sponsor. After passage in either the House or the Senate, the bill is transmitted to the other chamber where it follows the same procedure. When a bill is being considered by the whole of the legislative body, this is when a public campaign may have a huge effect. A letter-writing campaign, media event, or other act of public outcry may influence how the bill is voted on. Members of your coalition with a skill in grassroots organization will be the most effective organizers of this campaign. Efforts of the primary advocate devoted to constant contact with legislators and the political process ensure the campaign moves forward. After approval by the second chamber, the bill is sent to the state governor.

Action Taken by the Chief Executive
Obviously, governors have the opportunity to veto legislation. Lobbying the
executive branch may be important for passage of a bill, unless legislative support will provide veto protection.

Further consideration may be given to a public signing. If this action is important, physicians should meet with executive branch staff immediately after passage. Referral of laws from legislative to executive branches can be very fast. Although a discussion of working with the media is outside the scope of this article, it is important to note that the media can be both useful and harmful to your efforts. Writing letters to the editor or an op-ed piece in the paper is generally safe and effective. We recommend getting assistance before initiating contact with television or radio media. Most hospitals have media relations personnel who are helpful in arranging media contacts and very familiar with how to engage the media.

**GETTING IN THROUGH THE BACK DOOR**

Legislative change is immensely difficult and time-intensive, and often, societal change is best accomplished by reforming regulations as opposed to enacting a new law. Laws typically contain only vague instructions about how they will be carried out. Regulating agencies, and, in our particular field, the DOH, are typically charged with developing procedures that dictate exactly how a law is interpreted and enforced. Regulatory reform often occurs without much press or opposition, so it may be easier to accomplish your goals through regulation reform. It is important to note that the DOH may not be interested, or may even disagree with the reform, particularly if it imposes an undue regulatory burden on the agency. Early in our efforts, some in the Rhode Island DOH were skeptical about the importance of making prenatal HIV testing opt-out. Provision of easily interpreted statistics and enlisting the assistance of a dedicated individual in the New York DOH quickly secured support of our efforts.

Finally, frequent contact with the DOH allows you to keep apprised of other opportunities in which public opinion is sought. Public comment periods are typically required and offer the chance to advocate for your cause both in writing and through various open forums. In our efforts to create a mandatory newborn testing program, it was extremely powerful to bring a cohort of residents and senior physicians dressed in white coats to the public forum to exert pressure on the DOH to mandate the change.

**THE OUTCOME: A NEW HIV LAW IN RHODE ISLAND**

As a result of our legislative efforts, we ultimately achieved passage of a bill in Rhode Island that reduces barriers to HIV testing in pregnant women. This legal reform was by no means straightforward but in the end, both legislative chambers passed the bill mandating opt-out testing in pregnancy, nearly unanimously. In September 2008, our advocacy team convinced the Rhode Island DOH to pass regulation requiring immediate testing of newborns after birth when a maternal test result is not documented. A year later, 2 authors served on a congressional commission and eventually passed a second bill that made all HIV testing in Rhode Island for all individuals, regardless of age, opt-out.

Since passage of these reforms, testing rates in pregnant women have risen from 53% to 99% (N.A., B.A., R. Neale, T. Flanigan, C.G. Beckwith., unpublished data, August 2009. There has been no child whose HIV status has been unknown at, or shortly after, birth. Only 1 child has exhibited vertical transmission, and in that case, this transmission was despite appropriate and timely initiation of therapy.

This project, from inception to passage of mandated newborn screening, lasted 2 years and resulted in a direct savings of health care costs in the millions. Dramatic societal improvements can be achieved through advocacy efforts of physicians. Hospitalists are uniquely qualified to effect these changes through an increased awareness of patterns of disease, their unique position in society, and a flexible schedule that allows active participation in the political process.

**REFERENCES**


