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To cite this article: Christian Downs (1999) Anatomy of a Legislative Victory: Clinical Trials Bill Advances in Illinois, *Oncology Issues*, 14:4, 7-7, DOI: [10.1080/10463356.1999.11904849](https://doi.org/10.1080/10463356.1999.11904849)

To link to this article: <https://doi.org/10.1080/10463356.1999.11904849>



Published online: 17 Oct 2017.



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Anatomy of a Legislative Victory: Clinical Trials Bill Advances in Illinois

by Christian Downs

During the past legislative cycle I had the privilege of assisting the Illinois Medical Oncology Society (IMOS) with a cancer clinical trials bill before the legislature. It was an excellent opportunity to witness firsthand the immense work and patience necessary to navigate a bill through the legislative process.

The bill called for state insurers to cover the routine patient care costs for their enrollees participating in cancer clinical trials. At the time the bill was introduced, only two states had passed similar legislation, Rhode Island and Maryland; Georgia had passed a law mandating coverage only for children. Previous clinical trials legislation had been voted down in Illinois.

This year the clinical trials bill was subject to a ferocious and often personal attack from small business insurers who argued that clinical trials coverage would be cost-prohibitive. Legislators had to be convinced that the bill was not a "mandate" and that the costs of such a program would be negligible.

The House version of the bill passed by an overwhelming margin. Unfortunately, a companion bill in the Senate stalled in the Insurance and Pensions Committee. Furious lobbying and negotiations took place among legislators, those interested in quality cancer care, and lobbyists from the insurance industry. After some procedural maneuvering, a bill was reported out of committee, and negotiations began in earnest.

Eventually a deal was reached requiring insurers to offer coverage for Phase II, III, and IV clinical trials approved by the federal government

and conducted at multiple sites around the state. The bill also required the Department of Insurance to conduct a study on the cost of clinical trials. This version passed both houses and, at press time, awaits the governor's signature.

LESSONS LEARNED

Here are a few key ingredients for any successful legislative endeavor:

Dedicated and tenacious advocates. This bill reached the governor's desk through the tireless efforts of two medical oncologists, Dr. Edward Braud, president of IMOS and treasurer of ACCC, and Dr. James Wade, a past president of both IMOS and ACCC. These physicians provided testimony, met with legislators and lobbyists, and carried the IMOS flag. IMOS membership was also instrumental in writing and contacting state representatives and key leaders on the Senate Insurance and Pensions Committee. Patients, nurses, administrators, and patient advocates also voiced their concerns to legislators.

Their efforts were bolstered by Sen. Kathleen Parker (R-Northfield) and Speaker Michael Madigan (D-Chicago). The groundwork for this bill was established by former ACCC Director for Government Relations Jamie Young and the late Sen. Penny Severns (D-Decatur). Betsy Mitchell, the bill tracker for IMOS, and Randy Whitter from the American Cancer Society were critical in reading the legislature and working with opposing lobbyists.

Economic information. Legislators make many of their toughest decisions based on answers to the simple question, "What will it cost?" Providing them with solid economic information is critical. This point is especially true at the state level, where many legislators do not have staff

available for economic analysis.

In Illinois, data were available from multiple sources to address legislators' cost concerns about clinical trials. This information was then presented in a way that legislators could quickly and easily understand: The number of individuals likely to enter a clinical trial was compared with the total number of insured in the state, which helped put the cost-per-insured into perspective. Such data were crucial in responding to opposing lobbyists who claimed that any clinical trials coverage would put thousands of people out of work.

Coalitions. The most effective way to move a piece of legislation forward is to identify other groups that have similar interest in the bill's outcome. IMOS worked closely with the American Cancer Society, patient advocacy groups, Blue Cross/Blue Shield of Illinois, and several other insurance organizations, which prevented the opposition from framing the issue as medicine versus insurance.

Willingness to negotiate. In Illinois, the original bill required all insurers to cover the cost of clinical trials. Lobbyists for small business insurers countered with a program in which patients would apply to a board before being admitted into a clinical trial. Finding this unacceptable, IMOS vigorously argued that any proposal preventing patients from easily accessing a clinical trial would defeat the purpose of the legislation. After contentious debate, both sides agreed that requiring an insurer to offer coverage was the best they could get.

Working any bill through a legislative body is a difficult and time-consuming task. In the end, a committed group of advocates armed with good information and a network of supporters negotiated a successful bill. ■

Christian Downs is ACCC director of provider economics and public policy.