

Tips for a Successful Campaign in Support of Oral Anticancer Treatment Access Legislation

Outlined below are some lessons gleaned from several years' worth of work securing (and sometimes temporarily failing in our attempts to secure) legislative solutions for oral anti-cancer treatment access laws.

Identify the Issue:

Where does the issue stand currently? Has a bill been introduced in the past? What documentation do you have to prove it is an issue in the state? Do you have supportive studies? Is there a patient case demonstrated? Can you cite the future need given the projected growth of oral products in the cancer treatment pipeline? The success of any initiative can hinge on whether or not decision-makers perceive there to be a direct need.

Identify the Ultimate Goal:

Start with the end in mind and be specific. It's hard to hit an unidentified target. Be clear on the components that you want or need and bear in mind that the ultimate goal is parity in out of pocket costs for anti-cancer drugs, however that can be achieved.

Understanding that compromise may be necessary at a later point in the debate, consider the provisions that you are willing to negotiate on and which ones are off-limits. Consider what provisions you could live with in order to reach the larger goal. Key questions to think about in regard to this should include:

- Are you going to approach the issue with a cap on monthly costs?
 - If you do seek a cap, what should the dollar amount be?
 - If you do seek a cap, begin negotiations at \$50 knowing that the high limit cannot be more than \$100. (Studies have shown that the rate of patient abandonment of prescriptions increases substantially as out of pocket costs grow over \$100. These studies are available on the SPEAC website.)
- Are you willing to allow an annual cost increase tied to some economic marker? If so, which one?
- How will you respond to the suggestion that "sunset" language be added to the legislation (meaning the bill would need to be renewed after a certain time period)?

Identify the Players:

Key Legislators: Who to consider as a possible bill sponsor

A good bill sponsor is one that is committed to putting the advocate's criteria first, no matter what the insurance lobby comes to the table with, and will ensure that the patient advocacy community is always at the table. Consider the following key points when identifying a potential bill sponsor:

- Who has introduced similar legislation? What is the legislator's voting record/political philosophy?
- Has the legislator had success in passing legislation and a track record of championing his or her legislative priorities?
- Who has a successful history bringing bills that have served patient populations but were opposed by the insurance industry (Autism, clinical trials, cancer screening)?
- Is there a legislator whom other legislators respect in general or on health care issues?
- Is there someone who has been a "go to" on physician/pharmacist/patient issues?
- Is the potential sponsor in the majority party or otherwise in a position of influence?
- Does the sponsor or someone on his or her staff have a personal connection to cancer? (Be cautious: passion for an issue does not always equal political power or strategic thinking.)
- Review the legislator's donation records to anticipate objections or potential influencers.

Key Administrators: Ensuring survival beyond the legislature

Not every effort must begin or end with the legislature. Some states have found success investigating options for coverage via the administrative structure of the state, including the Governor's office and the Insurance Commissioner. Remember that it is always good practice to have an understanding of where the executive branch sits in relationship to your legislation. Sowing the seeds of acceptance and support for your measure with the Governor's team at the start can help to ensure that, should you be utilizing a legislative approach, the bill will make it through final passage.

Remember also that once the bill has been passed, responsibility for its implementation will be through the executive branch. It is not only necessary to ensure that legislation is properly implemented, but also that it continues to be enforced in a manner that clearly expands patient access to anti-cancer therapies. Follow up with the proper administrative structure in your state after any legislation is enacted is vital to ensuring the protection's survival.

Key Community Components: Determining your allies

Consider who among your organization and other partner organizations has a personal story and is willing to share. Consider also the timing of sharing stories. When do you need the additional boost that a good story can provide? Try to anticipate the points at which the bill will be stuck or will be in need of extra support. How has the legislature responded to constituent or patient stories in the past? Are they more persuaded by data or by personal stories? Structure your arguments based on the needs of the audience.

Coalitions are often the lifeblood of any effort, however it is important to ensure that all parties are working in concert. Investigate which partners are natural allies for supporting your issue. Disease groups and healthcare advocacy organizations are always safe bets, but consider what other businesses (e.g. the biotech/life sciences sector), hospitals/health systems, physician groups, etc. may have a stake in the issue.

In the first coalition meeting, it is important to have everyone (patient advocates, industry partners, providers) agree to the same goal, strategy, legislative language, and messaging. Ensure everyone is in agreement along the following issues:

- Bill Language
 - Starting language
 - Acceptable amendment language
 - Cap?
 - Sunset provision?
 - Payer expectations?
 - Consumer Price Index adjustment?
- Talking Points
 - Come to an agreement about which talking points will work in your state and focus your talking points on what issues are most salient to lawmakers.
 - SPEAC maintains a variety of talking points documents. Save yourself the work and borrow liberally from them.
- Media Plan
 - Bill/Coalition name
 - Spokespeople
 - Timing of efforts
 - Should the coalition engage a media consultant?

Identify the Strategy:

You know where you want to go now how do you plan to get there? What resources do you need? It is the responsibility of the patient advocates to convey to the relevant parties what we will and will not accept from a final outcome. You must also put thought into whether you want to utilize a legislative or regulatory approach to achieving oral parity.

Research Required: Do your homework. Prepare, prepare, prepare!

Information and understanding of your state legislature and executive is vital.

- Party in control: Senate, House and Governor (Majority party= majority sponsor)
- Term Limits? Elections? District Information? Whom do they serve and who has a large presence in their districts? (Hospitals, clinics, etc.)
- Review Legislators' websites. Look at awards won, committee membership, issues discussed, bills introduced.
- Identify chairs of committees: Health, Insurance, Rules, Appropriations, etc.
- Members of the committees and who views the issue positively (Committee Staff).
- Identify conference committee members in preparation for potential reconciliation of House and Senate bills.
- Legislative Leadership: Speaker, President Pro Tem, Majority Leader, Majority Whip, Floor Leader, etc.

- What are the various caucuses and factions within the legislature?
- Strength of Opposition: What is the other side's story? Facts to counter opposition? Do you have the issue broken down into pro and con arguments to support authors and leadership?
- Learn the rules and procedures of the House and Senate. Understand how the bill is introduced, how the committee system works, when the bill can be brought to the floor for a vote and where the Governor fits into the process. Study the rules. Speak the language.
- Know Deadlines (House and Senate) including bill introduction, pre-file, crossover, etc.

Prior to introduction of the bill, talk with the sponsor to discuss a specific pathway for the legislation. Is there are particular committee that you'd prefer the bill to be run through (or one that you'd prefer to avoid)?

Identify the Tactics:

List out the tangible steps needed to bring the strategy to life. Consider:

- Advocates and patients: Build the coalition of patients and advocates. Develop the specific, crystal clear message that is agreed upon by the team and can be supported. Match with legislators and visit Legislators in their Districts before session.
- Lobbyist: Identify which lobbyist will support, educate them, provide materials and offer legislative visit support. Everyone should have clear assignments.
- Legislative Champion/s: Educate and provide information, testimony and support. Ensure that your legislative champion knows the opposition arguments and how to respond effectively. Match with other legislators throughout the country that have been successful with the issue.
- Media: Which coalition members (advocates, other organizations) have good media contacts? What part(s) of the state are those contacts in? Who should be the main liaison with the press?

Identify the Messenger(s) and the Message:

Who are the people who should be the primary communicators? How is the message different when the communicator is a patient instead of a pharmacist or clinician?

Consider also the materials that you will use to communicate that message. Do you have a simple summary explaining the issue and a more complex document outlining the issue for those who want the expanded information? Bill authors/co-sponsors/Leadership can benefit from the preparation of "briefing books" containing all research on the issues in a condensed manner, including handouts to answer major questions that opposition will raise. Committee hearings also benefit from prepared books, however consider more condensed booklets for committee members, particularly if these can be made specific to each member's district.



Suggested Messages:

- Do use SPEAC's templates and talking points if you need assistance.
- Avoid stressing convenience as a reason for oral medications. The issue isn't about patient choice; sometimes the only anti-cancer medication available is in pill form.
- Stress that chemotherapy is chemotherapy, regardless of the delivery method.
- The way we treat cancer is changing. Patients shouldn't be discriminated against simply because the drug they need to survive is only available in pill form
- Always have a patient story to bring the point home.
- Don't forget to include the oncologist/health care provider perspective.

Key Resources: SPEAC Document Library

SPEAC has created a document library to support materials to educate legislators, advocates and the media. These are:

- Model bill language
- Sample one page issue overview that you can customize for your state
- National map of states with enacted laws
- National Landscape of State Oral Parity Laws - Gives a scope of the nuances between each state
- State Fiscal Impact Chart - Easy to read chart that compiled studies from other states
- Sample myths and facts document/FAQ document
- Oral Parity and the ACA document
- Sample Action Alert Language