Health Policy and Advocacy

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KEYWORDS

• Advocacy • Health policy • Physician leadership

KEY POINTS

- Engagement in health policy and advocacy is critical to the future of the practice of medicine.
- The 3 major urologic organizations (American Urological Association, American Association of Clinical Urologists, and Large Urology Group Practice Association) evolved different pathways to engage the national and state legislative and policy apparatus.
- Urology engagement has resulted in significant impact on the practice of medicine on both state and federal levels from both legislative and regulatory perspectives.
- The importance of individual contributions from both time and money to political efforts cannot be overstated.
- Increasing diversity among those involved in leadership and advocacy is needed to amplify urologists' voice over the coming years.

PHYSICIAN ADVOCACY IN HEALTH POLICY—HOW? WHY NOW? AND WHY ME?

The scope of interest of those pursuing medical careers has greatly changed—30 years ago, other than the occasional associated PhD, medical students an physicians rarely pursued degrees beyond an MD. Physicians now commonly pursue additional studies outside of their medical training, whether it be degrees in law, business, hospital administration, or public health—the Association of American Medical Colleges reports that from 2006 to 2014, the number of physicians graduating from medical school with dual degrees increased by more than 50%,[1] amplifying the importance of expanded expertise to aspects other than direct patient care. The ability for practicing urologists to enter the arena of health policy and advocacy has expanded as their knowledge base and experience has increased; although it may not always seem the case, the input of practicing physicians of a variety of backgrounds is actively sought by legislators and regulatory agencies because this input is essential for patients' access to the level of care that current knowledge and technologies.

As with most life endeavors, the most daunting step in political engagement is the first one. Many practicing urologists may feel unqualified to comment on health policy, may feel uncomfortable engaging with the political apparatus, and have very real concerns about whether this engagement can produce tangible results. Perhaps most importantly, even interested physicians struggle find time to be engaged effectively in this arena with commitments to amass relative value unit expectations, research activities, Centers for Medicare & Medicaid Services (CME) requirements and other certification burdens, and time for family life and personal pursuits. Given these constraints, typically, there is a perceived need or threat that overcomes these obstacles to engagement and overcomes inertia. Whether it be the historical threat to lithotripsy partnerships defeated by the American Lithotripsy Society,[2] the need to protect dedicated armed forces

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personnel from wartime injuries,[3] challenges to the ability to develop integrated care models,[4] or unelected regulatory bodies making medical determinations potentially depriving patients of life-saving diagnostic testing,[5–7] to name but a few, many physicians involved in health policy were galvanized by a specific event. In addition to responding to events, such as these, organized urology societies provide regular input to legislative and regulatory bodies via engagement through commentary on the Medicare Physician Fee Schedule and Outpatient Prospective Payment System annual rules. Consequently, there is an organized infrastructure in place for physicians who become motivated to engage for whatever reason.

That said, despite potential difficulties in becoming part of the process, it is the overwhelming experience of those who engage in policy and advocacy that the benefits to engagement have far outweighed the challenges in becoming engaged. Career satisfaction improves with involvement, the likelihood of burnout decreases, and it helps develop strong physician leadership skills. Physician leaders explain complex medical issues to lay individuals in government that typically view policy issues through a political lens—understanding the real-world impact and potential unintended consequences of their actions is vital to the job performance of legislative and regulatory agencies. Legislators, particularly in the US House of Representatives, welcome the input of physicians practicing in their communities to a degree that is surprising to those starting in the advocacy process. Eventually, as relationships develop, these leaders view physicians that engage with them not only as advocates but also as a resource and actively seek input pending legislation and regulations, which can have profound effects on a urologist's ability to practice. The corollary to this also is true—physician leaders can translate complex legislative and regulatory processes to fellow physicians to help colleagues navigate what for many can be bewildering and rapid changes to their practice.

LEGISLATION VERSUS REGULATION—ADVOCACY BY SPECIALTY SOCIETIES

For many years, the urologic community met for the Joint Advocacy Conference met every spring in Washington, DC. This meeting, comanaged by the American Association of Clinical Urologists (AACU) and the American Urological Association (AUA), included briefings on the health policy priorities of organized urology and culminated with visits to Capitol Hill to engage with congressional leaders. And although the 2 groups separated after 2017, each has continued its own meeting annually. The Large Urology Group Practice Association (LUGPA) adopts a somewhat different strategy, one of highly targeted engagement through focused bipartisan political giving to members of the key committees of jurisdiction, as discussed previously. Thus, rather than a single large gathering of physicians, the LUGPA typically conducts small group meetings every 6 weeks to 8 weeks. Regardless of approach, this immersion into how health policy affects the day-to-day practice of medicine and the power of participation in advocacy is unique and impactful. Regrettably, the recent public health emergency has severely curtailed these interactions, and, although they continue virtually, clearly are less impactful that the face-to-face interactions previously employed.

Despite the existence of highly organized policy and advocacy infrastructures, it is remarkable that the spectrum of the activities available within the AUA, AACU, and LUGPA still is a surprise to many urologists. Part of this is a consequence of medical training—although it is clearly a first responsibility to understand the disease processes of the genitourinary tract and how to treat them with a combination of medication, surgery, and lifestyle modification strategies, there is no time dedicated within residency education requirements to health policy. Those who engage in policy feel this is a tremendous shortcoming because it does no one any good to learn a skill that cannot be utilized due to legislative or regulatory fiat. Happily, this is changing. The AUA has increased its focus on programs through to deliver grand rounds lectures on these very subjects, exposing the newest in the ranks to health policy. The AUA also offers career development programs, which include its leadership program for urologists in the first decade of practice, the Holtgrewe Fellowship for residents and fellows, and the Gallagher Health Policy Scholarship for those in practice. Health policy activities on the section level and committees on the national level also are powerful ways to contribute time and energy. The legislative affairs committee within the Public Policy Council assembles the AUA legislative priorities are released by the AUA board every year based on the general membership's preferences.

The LUGPA Forward program seeks to engage younger practitioners, creating a subgroup of physicians who recently have completed residency. Representatives from this group participate in LUGPA's sophisticated political affairs and health policy apparatus. These committees rely heavily on the development of long-term relationships by highly experienced physician leaders. This system

creates in effect an apprenticeship program, where engaged younger physicians participate in LUGPA events on a regular basis, eventually conducting them on their own. This has enabled LUGPA, despite being a relatively fledgling organization, to develop and maintain a robust advocacy infrastructure.

The AACU's health policy apparatus focuses on state advocacy through the state society network. This is an essential component to policy work because many regulations and laws are promulgated on the state level—given the degree of scrutiny on every action on the federal level, actions on the state level that potentially are impactful on the practice of medicine can happen quickly and without much oversight. By monitoring state activity, the AACU successfully has triggered efforts to combat adverse legislation in several states, often engaging other specialty societies and stakeholders. In addition, AACU is fully engaged with AUA and LUGPA on federal issues.

Communication between specialty societies in urology continues to improve. Physician leaders in policy and advocacy understand that, although different groups may have different constituencies and priorities, the need for urology as a specialty to speak with single voice never has been greater. The health policy apparatus on both physician and staff levels for the AUA, AACU, and LUGPA communicate regularly and have scheduled meetings no less than monthly. Through these efforts, intersociety communication and collaboration are at their highest levels, greatly benefitting the specialty as a whole.

At present, skills needed to become effective advocates for patients are not part of the residency curriculum; certainly, there is a concerted effort to enhance awareness to the need for these efforts early in urologists' careers.

UROTRAUMA BILL—RELATIONSHIPS BUILT AND LESSONS LEARNED

The wars of this century in the Middle East have seen increased use of improvised explosive devices, which explode typically from below a solider who may be riding in a vehicle. This can result in injuries that more often cause lower extremity and pelvic damage—this is in contrast to previous conflicts, when projectiles were used that were more likely to cause injuries to the head or torso and upper extremities.[3]

As the principal providers of care to the genitourinary tract, management of these injuries falls in large part to urologists; as such, many other practitioners simply were unaware of the magnitude of this problem. Consequently, there was no. Unlike programs already in existence for other organ systems (such as traumatic brain injury), there was no organized effort to evaluate the impact of and optimize treatment of these novel pelvic injuries. As such, it fell to the urologic community to advocate for men and women of the armed forces who risk their lives.

This resulted in the development of the Urotrauma bill, which directed the Department of Defense to establish an entity devoted to care for military personnel who suffer injuries to the urinary tract in combat.[8] This effort diverged from prior policy work in that rather than seeking to thwart adverse legislation and rulemaking, The Urotrauma legislation was a proactive piece of legislation. Any piece of legislation, regardless of how noble in purpose and nominal in cost, is extremely difficult to pass.

This legislation provided important learnings on the mechanics of promulgating legislation. Seeking the appropriate sponsors and cosponsors, having bipartisan champions in both the House and the Senate, identifying the proper committees through which to introduce the bill, developing budgetary offsets, and navigating the legislative schedule were merely some of the challenges that needed to be overcome.

The cynicism physicians feel for lawmakers is reciprocated to a certain degree, because legislators are fearful of angering one set of constituents when they act in favor of another; in addition, any ask that has an impact on budgets have a much harder hill to climb to become law. Consequently, although the budgetary ask was a mere $4 million and no legislator was opposed, this bill required substantial effort over several years to be passed. Through these efforts, that resulted in no economic gain to urologists but completely focused on the nation's wounded warriors, the efforts to pass this legislation built connections with Senate and House members and changed the optics by which the specialty is viewed. The relationships on the Hill built on this moral and unselfish ask have served the specialty well for all of the years since then. Bills often take several sessions of congress to pass, and the party in control of the agendas and the committees may flip multiple times during that time. Having broad support from both parties ensured that this legislation proposal would be reintroduced with each new session. With persistence over several years by dedicated urologists and congressional sponsors, aided by joint advocacy by the AUA, AACU, and LUGPA, the Urotrauma bill language eventually was included in the National Defense Authorization Act of 2014 and signed into law.

THE US PREVENTIVE SERVICES TASK FORCE AND PROSTATE-SPECIFIC ANTIGEN: AN EXAMPLE OF MULTIDISCIPLINARY ADVOCACY

As most urologists are aware, in 2012, the US Preventive Services Task Force (USPSTF) issued a grade D recommendation on the use of serum prostate-specific antigen (PSA) as a screening tool for the early detection of prostate cancer.[5] Most urologists also are aware that this recommendation was updated to a grade C recommendation, which emphasizes shared decision making; however, most are aware of neither the complexities regarding the USPSTF recommendations nor the urology community's sustained response. This action represents a comprehensive case study on the power and importance of physician leadership and advocacy.

To understand the complexities that arose with advocacy around the USPSTF PSA recommendations, it is necessary to understand the history of the USPSTF specifically and of Medicare preventive services in general. When Medicare was signed into law in 1966 by President Lyndon B. Johnson, it was designed to cover acute care; preventive services (eg, checking blood pressure in otherwise healthy individuals) were not covered benefits. Despite the ongoing and increased recognition of the value of such services in enhancing health, the CMS as a regulatory agency did not have authority to add benefits specified under statute—any alterations of Medicare benefits had to come from congressional legislative action. To accomplish this, by 1980 more than 350 bills were introduced to cover these types of services.[9]

To help provide guidance on these services, in 1984 the USPSTF was created with representation from the disciplines of internal medicine, family medicine, pediatrics, behavioral health, obstetrics-gynecology, and nursing. At the time of formation, the USPSTF served as a purely advisory entity; there was no obligation for any regulatory agency, Congress, or provider to follow their guidance. As such, the USPSTF was not required to comply with 2 key federal oversight acts, the Federal Advisory Committee Act and the Administrative Procedure Act. As an advisory body with no binding economic authority, it was exempt from rules, including providing a public comment period to its recommendation, transparency of its process of appointing members, release of methodology and communications on how the members reached their conclusions, and exemption from the freedom of information act, among others. Of particular consternation to specialty societies is that not only is there no representation of specialists directly responsible for providing the services being reviewed but also there is no requirement for the USPSTF to consult content specific experts when considering preventive care.

Even with the creation of the USPSTF, addition of preventive services proved challenging—by 1993, only 4 of 44 services recommended by the USPSTF for the elderly were covered by Medicare.[9] The problem of benefits lagging progress in preventive services was addressed more formally in 2008 with the passage of the Medicare Improvements for Patients and Providers Act (MIPPA).[10] Although preventive services went through a process of National Coverage Determinations, the views of the USPSTF were given substantial credence—CMS was granted the independent authority to add services deemed reasonable and necessary provided they received an A or B recommendation from the USPSTF. Although MIPPA did not allow for denial of services based on USPSTF recommendations, for the first and only time in US history, an advisory board not subject to federal oversight was granted the authority to make recommendations that result in changes to payment policy.

With the passage of the Patient Protection and Affordable Care Act of 2010 (ACA), colloquially known as Obamacare, the authority of the USPSTF was greatly expanded.[11] The CMS were mandated to cover services with a USPSTF grade A or grade B recommendation; ominously, the authority to deny services with a grade D recommendation was created and, by inference, the CMS were granted the authority to deny services simply if the USPSTF elected to provide a recommendation. As such, the authority to cover or deny services was placed solely in the hands of an agency completely outside the federal regulatory oversight process.

This history set the stage for the USPSTF recommendations regarding prostate cancer screening. To be clear, 2012 was not the first time that the USPSTF had evaluated PSA-based prostate cancer screening. In its prior reviews, the USPST had issued I recommendations, meaning that there was insufficient category I data to evaluate the efficacy of the test.[12] That changed in 2012 with the issuance of a grade D recommendation, which went so far as to say the harms of a simple blood test outweighed any potential benefits.[5] This was a 1-size-fits-all policy and did not consider the impact of family history, environmental toxin exposure, or race on prostate cancer risk—all clearly egregious oversights.

The response of the urologic community to the USPSTF grade D recommendation was swift,

varying from serious concerns to outright condemnation. As a baseline, the science surrounding PSA testing underwent an expert-based review. The AUA published updated prostate cancer screening guidelines[9] that emphasized shared decision making; similar efforts were endorsed by the LUGPA and the AACU. Simultaneously, there was broad outreach to the primary care community, both informal and formal, on the importance of PSA testing, particularly in high-risk populations. Perhaps most importantly was engagement with patient advocacy groups, both broad based and representing specific constituencies (ie, veterans exposed to Agent Orange and the African American community).

These foundational advocacy efforts proved critical in 2015, when concerns regarding denial of services were proved valid. At that time, the National Quality Forum quietly proposed a rule derived from the USPSTF recommendation that would penalize primary care physicians up to 2% of their Medicare reimbursement if they ordered screening PSAs on their patients.[13] Clearly, this would have had a chilling effect on early diagnosis of prostate cancer, and although the tsunami of objections by the urologic community thwarted this misguided initiative,[14] this clearly exemplified the need for close monitoring and immediate action to protect access to care for patients.

Although advocacy on the federal level had commenced immediately on the release of the USPSTF recommendation, the actions by the National Quality Forum and dramatic data that suggested increasing death rates from prostate cancer galvanized continued and expanded engagement.[15–18] The urologic community did not focus solely on PSA testing; historically, Congress is reluctant to act when presented with differing expert opinions, particularly when an advisory board is empowered to make policy recommendations. Instead, the urologic community aligned with other stakeholders to educate lawmakers on the process by which the USPSTF operated; remarkably, the fact that the USPSTF was able to operate without congressional oversight was surprising to legislators.

The combination of input across various specialties with engagement of patient groups proved powerful. Congressional leaders recalled the USPSTF recommendation against screening for breast cancer; in fact, based on immediate and aggressive response of breast cancer patient advocacy groups, language carving out breast cancer screening from USPSTF authority was included in the ACA. As such, there was no shortage of sympathetic members of Congress, many of whom either were prostate cancer survivors themselves or had a close relative battling the disease. Ultimately, this led to the USPSTF Transparency and Accountability Act. Rather than focusing on a single recommendation for a single disease state in a single specialty, this legislation required that the USPSTF adhere to the same transparency and oversight requirements required of every other federal advisory committee and to consider the view of content-specific experts when promulgating recommendations.

The impact of these advocacy efforts on the USPSTF process has been profound.

Although the USPSTF has engaged in its own advocacy efforts to prevent passage of the USPSTF Transparency and Accountability Act, the specter of legislative changes to their mandate has resulted in a substantial change in the process by which they promulgate recommendations, with much greater visibility into the decision-making process and inclusion of appropriate subject matter experts. The requirement to consult content experts when evaluating services. A direct consequence of these reforms was the 2018 revisitation and modification of the grade D recommendation on PSA-based prostate cancer screening to a more appropriate grade C recommendation. Efforts did not end there; in 2019, thanks to diligent advocacy efforts by urology practices within the state, New York became the first state in the United States to mandate no out-of-pocket insurance coverage for PSA testing for men over age 40.[19]

POLITICAL ACTION COMMITTEES AND FUNDRAISING

A part of the political process that many find distasteful is fundraising; this includes both those asked for and receiving contributions. From the moment a member of Congress is sworn into office, that representative immediately must think about the next election, which in the US House of Representatives is every 2 years. A significant amount of time for all members on both sides of the aisle is devoted to fundraising efforts. And although any citizen can engage with the political process, the opportunity to interact with an elected official during a fundraising event affords the opportunity to engage in what often is a much smaller and more social forum. And although there can absolutely never be any suggestion or expectation that any political contribution can result in a legislative quid pro quo, the opportunity to present a point of view that otherwise may not be heard is invaluable.

In broad brush strokes, there are 2 general mechanisms by which fundraising is conducted,

via representative entities, such as political action committees (PACs), or by direct giving. PACs are a tool under the authority of the Federal Election Commission that allow pooling of donations from a defined group of citizens so the contribution can be given in larger amounts to selected candidates. There are 2 PACs that exist in the urology community—the AUAPAC, which is associated with the AUA, and UROPAC, administered by the AACU. In general, a contributor to an organization's PAC must be a member of the organization and a US citizen. LUGPA also engages in political giving by asking for member group practices to donate to individual fundraising events to specific congressional members. By law, these 2 entities must act independently and cannot coordinate giving.

The advantage to having multiple organizations participating in the process is that it does provide multiple vehicles for political giving; this must be balanced against the possibility that political donations are split between different entities. That said, although political giving cannot be coordinated between organizations, messaging certainly can be. Because different urologic societies have somewhat different legislative priorities and constituencies, having similar messaging delivered from different viewpoints broadens the specialty's presence on Capitol Hill. One way to increase the volume of advocacy messages is by having it repeated by different groups throughout the year. Having a mechanism to donate gives a specialty a place at the table and a mechanism for congressional members to access opinions. AUAPAC is in its infancy but already has contributed to 24 individuals. UROPAC has more of a history and also contributed to a similar number of lawmakers over the past year, with total contributions by its members in the 6-figures yearly. LUGPA works under a system of individual giving and not through a PAC, and its activities on the Hill have been extensive and hugely effective in favor of urology. All 3 organizations aim to distribute those contributions equally among the 2 major parties and focus on members who have been supportive of the concerns and those who are on pertinent committees of jurisdiction. These organizations advocating for urology are nonpartisan with respect to political party but are hugely partisan in favor of patients' interests and urologist members.

THE CHANGING FACE OF PHYSICIAN ADVOCACY

One challenge facing urology is the demographic makeup of the specialty. Although it is a core focus of the urologic community to increase diversity within its ranks, historically, physicians who engage in advocacy tend to be older—for urology, this population is composed overwhelmingly of white men.[20–30] Messaging is more impactful when presented by professionals with varied backgrounds and practice environments. This is particularly important because much of the legislative work is done by legislative assistants, who themselves tend to be younger and from diverse backgrounds.

That said, efforts to enlist a more diverse group of physicians have been more complicated than just inviting individuals to participate. Younger doctors who are concerned about building their practices generally are focused on patient care and may not be fully engaged on the business and administrative aspects of their business. More senior physicians may not actively seek their opinions, and, when asked, the younger doctor may be more inclined to "go along to get along" than be viewed as a troublemaker within the practice—this is complicated further by the fact that the needs and goals of the younger physician may differ from the decision makers in the group. Given their work schedules and economic needs, unless the group specifically makes provisions for advocacy efforts, it may not be economically feasible for younger doctors to take time out of their schedules to engage in these processes.

Despite these challenges, the face of urologic advocacy has changed dramatically over the past decade. For example, at the 2020 AUA Advocacy Summit, 80 of the 300 attendees were students, residents, fellows, and young urologists, the largest number to date. The LUGPA Forward program continues to expand its membership, and opportunities for formal fellowships and informal apprenticeships in the advocacy realm continue to grow and be fully subscribed. Going forward, the urologic community needs to actively engage with medical students whose demographics are not well represented in the specialty to consider a career in urology.

SUMMARY

The nation's health care agenda is robust, and there are a significant number of issues having an impact on urologists nationwide. With a divided electorate and multiple stakeholders competing for limited resources, the need for engagement never has been greater. This need will be amplified as lawmakers and regulatory agencies seek to shift payments from volume-based to value-based models and will seek input

from subject matter experts to help guide these policies. Without question, the specialty of urology has laid a solid foundation in an impressively short period of time; the specialty needs to build on that foundation to ensure that their voice continues to be heard. That said, they cannot advocate effectively without the support and help of all involved in the care of urologic disease—voice, commitment, advocacy, and yes, financial commitment are vital to the future of the specialty.

DISCLOSURE

The authors have nothing to disclose.

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