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Pediatric Endocrinology Nursing Society Department

## Patient Advocacy: A Primer on Influencing Healthcare Delivery for Endocrine Patients☆☆☆



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Consider for a moment, the day-to-day work of an endocrine nurse: phone calls from patients and pharmacies, filing statements of medical necessity for treatments, obtaining prior authorizations from insurance companies on diabetes testing supplies, growth hormone, insulin pumps, gonadotropin releasing hormone agonists, and the list goes on. Whether we realize it or not, everything that we do daily as endocrine nurses starts with a policy or guideline. Unfortunately, however, policies do not come as one size fits all. Therefore, as nurses it is our responsibility to advocate for our patients beyond the bedside, phone call or insurance form.

Advocating for patients and families is the foundation of nursing. Merriam-Webster (2018) defines an advocate as “one who pleads the cause of another.” By this definition, for all intents and purposes, nurses are expert advocates. The American Nurses Association (ANA) (2015) Code of Ethics for Nurses with Interpretive Statements earmarks advocacy and involvement in health policy development in two of the tenets of nursing practice. Provision 7.3 in the ANA Code of Ethics, says “nurses must lead, serve and mentor on institutional or agency policy committees, within the practice setting” (p. 28).

According to the nationally recognized Gallup Poll, nurses have the highest ranking amongst twenty-two professions for honesty and ethics (Brennan, 2017). This is a trend that the nursing profession has maintained for over 16 years. This is also a trend that should encourage the profession to find ways to influence healthcare delivery. The Institute of Medicine has recommended that nurses “become equal partners with physicians and other healthcare professionals in redesigning health care in the United States” (IOM, 2010, p. 1). While this is a notion that seems relatively obvious, the recommendation has posed a challenge to many bedside nurses, advanced practice nurses and nurses in leadership positions because of antiquated politics associated with healthcare. But why should endocrine nurses care about this recommendation? How does following this recommendation impact our patients and the care we provide?

A simple search of the term “pediatrics” in the online Thomas Library, which reviews current legislative activities for the 115th United

States (US) Congress, yields 160 results. There are 20 bills currently in Congress that reference pediatric diabetes and 127 bills that involve the cost or coverage of pharmaceuticals (Library of Congress, 2018). While all of these bills may not directly affect our patients, it is imperative to stay abreast movement of legislation that has the potential to impact patients and families and speak out when necessary.

Additionally, while these numbers may seem large to some, the reality is that state legislative agendas may also have bills impacting pediatric care. Whether a nurse is involved in federal or state grassroots advocacy efforts, keeping track of national trends can keep a nurse informed and confident about the issues.

For instance, one recent trend that has had an impact on care of the children seen in endocrinology clinics is related to drug coverage and costs. Over the past several years, the cost of prescription drugs has become a hot issue in healthcare. According to the Kaiser Family Foundation analysis of drug trends, diabetes medicines are the most expensive of the top ten traditional drug classes and more than doubled the spending of the category ranking second (Kamal & Cox, 2017). Two practices seen in the pharmaceutical industry increasing cost to patients and families have spurred a request for policy change in many states across the US. These practices are pharmacy benefit manager clawback and insurance mandated step therapy.

Clawback occurs when a pharmacy benefit manager (PBM) handling prescription drug coverage on behalf of health insurance companies, increases the drug’s cash price to the consumer and then “pockets” a portion of the copay. In many instances, drugs may be less expensive to the patient if it is paid for out of pocket, rather than through insurance. However, pharmacists are not allowed to share this information because of “gag” clauses in pharmacist contracts with PBM (Norton, 2016). Over the past 3 years at least 28 states have enacted laws prohibiting “gag clauses” in pharmacist contracts, and 17 of these states passed the laws between March and September of this year (Cauchi, 2018). The trend became such a national phenomenon that US Congress passed the Patient Right to Know Drug Prices Act (S. 2554, 2018) and Know the Lowest Price Act (S.2553, 2018) in the fall of this year.

Step therapy, another recent legislative trend, is often required by an insurance company as a means to avoid paying for a more expensive, provider chosen medication. Before an insurer will cover certain prescriptions, a patient must “fail” a trial of a less expensive medication and a prior authorization must be completed. Step therapy is a practice commonly seen in the treatment of the Type 2 Diabetes Mellitus patient starting on oral therapy. Patients are often forced to start on a

☆ The Pediatric Endocrinology Nursing Society (PENS) is committed to the development and advancement of nurses in the art and science of pediatric endocrinology nursing and to improve the care of all children with endocrine disorders through the education of the pediatric healthcare community. To aid in achieving that goal, the purpose of the PENS department is to provide up-to-date reviews of topics relevant to the PENS membership and to the general readership of the Journal of Pediatric Nursing.

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medication that is more likely to cause side effects to see if they can tolerate it before a better-tolerated medication is covered. Last year alone, 18 states enacted laws modifying the restrictions imposed by step therapy (AAD, 2018).

Another current and modern legislative trend that impacts our patients is that which influences the care of our trans-gender patients. According to the National Center for Transgender Equality (2018), “ten states have introduced 21 anti-trans bills and 2 states are considering anti-trans ballot initiatives.” These bills vary from state to state, but cover a range of anti-trans topics; including bills that restrict access to health care, bills that limit a transperson's ability to update identity, bills that restrict access to restrooms and bills that restrict a transgender student's rights at school or in welfare settings.

Many nurses are intimidated by calls to action from professional organizations because they are novices at grassroots advocacy. Others will think it is too much of a time commitment to do effectively. However, nurses are perfectly poised to share stories to influence change in legislation for the betterment of patient outcomes. One nurse with one story can influence one vote and often that is all it takes. So next time you hear of an issue that seems unjust or causes you excess work for your patient, consider becoming a change maker. Start a conversation of why's and what if's. Your patients and peers will thank you for it.

## References

- American Academy of Dermatology (2018). Step therapy legislation. Retrieved from <https://www.aad.org/advocacy/state-policy/step-therapy-legislation>.
- American Nurses Association (2015). Code of ethics for nurses with interpretive statements. Silver Spring, Maryland. Retrieved from <https://www.nursingworld.org/coe-view-only>.
- Brennan, M. (2017). Nurses keep a healthy lead as most honest, ethical profession. Retrieved from <https://news.gallup.com/poll/224639/nurses-keep-healthy-lead-honest-ethical-profession.aspx>.
- Cauchi, R. (2018). PBM state legislation. National Conference of State Legislatures. Retrieved from <http://www.ncsl.org/research/health/pbm-state-legislation.aspx#map>.
- Institute of Medicine of the National Academies (2010). The future of nursing: leading change, advancing health. Retrieved from <http://www.nationalacademies.org/hmd/-/media/Files/Report%20Files/2010/The-Future-of-Nursing/Future%20of%20Nursing%202010%20Recommendations.pdf>.
- Kamal, R., & Cox, C. (2017). Peterson-Kaiser Health System Tracker. What are the recent and forecasted trends in prescription drug spending? Retrieved from <https://www.healthsystemtracker.org/chart-collection/recent-forecasted-trends-prescription-drug-spending/#item-start>.
- Know the Lowest Price Act of 2018 (2018). S. 2553, 115th cong.
- Merrimack-Webster (2018). Advocate. Retrieved from <https://www.merriam-webster.com/dictionary/advocate>.
- National Center for Transgender Equality (2018). State Action Center. Retrieved from <https://transequality.org/action-center>.
- Norton, J. (2016). The great big prescription drug clawback. National Community Pharmacists Association. Retrieved from <https://ncpanet.org/newsroom/details/206/05/20/the-great-big-prescription-drug-clawback>.
- Patient Right to Know Drug Prices Act (2018). S. 2554, 115th cong.
- Pediatrics (2018). In library of congress online. Retrieved from <https://www.congress.gov/search?q=%7B%22congress%22%3A%22115%22%2C%22source%22%3A%22legislation%22%2C%22search%22%3A%22pediatrics%22%7D&searchResultViewType=expanded>.