

# Legislative: Using the Tenets of Nursing to Address Policy Issues / Nursing Advocacy Beyond the Bedside: Using Research to Fight for Policy Solutions

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## Column

I began my college career by supplementing my nursing curriculum with political science courses, partially due to personal interest, but also to identify issues impacting healthcare as a whole, across the nation. I saw stories of patients unable to afford their insulin, or unable to make appointments. I was not okay with discharging my patients back to situations where they would be unable to take care of themselves. Although pairing nursing and political science was not unheard of (e.g., Representatives Lauren Underwood and Eddie Bernice Johnson held seats in congress during my freshman year), it was unconventional. I had to plan for my course load semesters in advance to ensure that I would stay on track with my nursing peers. I needed to convince my advisors that this was something I could handle to gain their permission to take overtime credits. I was unable to complete a major in another field due to university policies, even though my credits expanded beyond those of a minor.

My political science education took me to different areas than my peers. While they spent summers as nursing assistants or on co-op rotations, I interned in the Illinois and Congressional Houses of Representatives. Although we worked in vastly different areas, our goals were the same. Patient and constituent advocacy both come from an interest of helping others, identifying issues, and utilizing resources to provide a solution. I used the tenets of nursing, such as research, evidence-based practice, and communication, to assist constituents.

## Background

The United States Food and Drug Administration's (FDA) queer blood ban, a policy enacted in the 1980s, ([FDA, 2020](#)) was initially utilized to prevent national transmission of human immunodeficiency virus (HIV) prior to adequate understanding and mechanisms of testing for the infection among blood donors and products. In the 1980s, a deferral was necessary. The policy enacted a lifetime deferral for any MSM (i.e., men who have sex with men) who had been sexually active even once since 1977. The policy was reduced to a 12-month deferral in 2015, and to a 3-month deferral in 2020 ([FDA, 2020](#)). As an openly bisexual man, I was aware of the policy and had talked about it with my friends when my high school held a blood drive in our senior year. Although I found the policy to be discriminatory at the age of 18, I did not think much of it. At the time, I did not think there was anything for me to do.

Almost four years later, that was not the case. When the television series Grey's Anatomy covered the FDA's 3-month deferral for blood donations from sexually active queer men, two characters expressed their plan to fight it. Although this portrayal helped to raise awareness, it would fail to enact meaningful change; I decided to give it a shot.

Pride and Plasma, an organization to promote equality in biologics donations, grew from a need to influence public policy with research. Our goal is ambitious but focused: to fight for LGBTQ+ equality in blood, tissue, and organ donation. Although not well known, there are multiple policies and regulations that impact LGBTQ+ biologics donation, remnants of the HIV/AIDS crisis that still limit practices today ([n.d.](#)). Our initial team was composed of myself, another intern in Congresswoman Underwood's office, my fellow classmate Skylar Harris, and another college student conducting research on the MSM deferment at DePaul University. The four of us, all volunteers, began to research blood donor eligibility. Our team has since undergone changes as members transition to law school, medical school, and other pursuits. Other members who joined our fight included a city council candidate and pre-med students across the country. Our work is conducted remotely; thus, our team collaborates without a physical office and is not limited to a single time zone.

## Actions for Advocacy

My educational background of political science (policy) and nursing (science) uniquely suited me to address this issue. Along with a new team, we researched the history of the policy, previous advocacy efforts, global policy, current blood shortages, and potential routes for change. We contacted researchers and experts on the issue, talked to blood centers about the need for increased donors, and compiled our findings into a research brief ([Williams et al., 2022](#)). As we built our argument, we broke down each topic for members of the public, making our advocacy accessible to those without a healthcare or policy background; we applied the same communication skills utilized at the bedside between nurses and patients.

We submitted our research to the blood products advisory committee at the U.S. FDA. We spoke with members of the media, such as journalists and reporters, to raise awareness of the discrimination, our work, and the need for change. Almost two months after we argued in front of the FDA, a draft guidance on blood donor eligibility replacing the previous blanket deferral for MSM donors was released. The new policy, termed the “individual risk assessment,” ([U.S. FDA, 2023](#)) no longer considered a donor’s gender or sexual orientation. Previous questions related to gender and sexual orientation were replaced with an “individual risk assessment;” a policy in line with other nations and a step forward with science.

Pride and Plasma does not have legal non-profit status, although this is a future goal. This status will allow us to expand our team, provide internships for college students, train the next generation of advocates, and increase partnerships. This work follows the same process and procedure regardless of the policy we are working to change. We break issues down to the smallest pieces, and hopefully increase public understanding along the way. We continue to follow national and global trends, new research publications, and current shortages. After we find success, we never quit on a high note. We continue to return to the drawing board and address areas of improvement for the same work. Success is not the finish line for us; it is the justification that our work is critical. We use our successes to drive further innovation. Discrimination in healthcare is a result of prejudice and misinformation. Discriminatory policies enforce legally-required differential treatment. The Pride and Plasma team will not stop our fight until we have achieved LGBTQ+ equality in biologics donation.

The individual risk assessment was not the end of our work. I spent nine months researching and becoming an expert on LGBTQ+ biologics donation. Due to my work and the relatively small number of individuals qualified to discuss the FDA’s planned change, both Pride and Plasma and I emerged into the national spotlight. I felt an obligation to ensure that accurate and inclusive information was portrayed by those who were covering our story. I made a point to discuss the impact upon transgender, nonbinary, and gender-diverse blood donors; the FDA’s similar 5-year deferral for MSM tissue donors, and the HHS 30-day policy for organ donations from MSM donors ([Jones et al., 2020](#); [U.S. FDA, 2007](#)). We worked to portray this as an issue impacting many members of the LGBTQ+ community, rather than only cisgender gay men, as previous covered.

Since then, Pride and Plasma submitted four additional research briefs to the FDA: three on the 5-year queer tissue ban (where any donors who report sexual activity with another man in the 5-years prior to death are unable to donate their tissues) ([Williams et al., 2023](#)), as well as one highlighting the need for federal policies inclusive of gender-diverse blood donors ([Williams, 2024](#)). Since acceptance of this column for publication, a third research brief to the FDA has been drafted for November of 2024. I have been quoted and featured in publications including the Washington Post and Insider; and have appeared on PBS Newshour, CBS News, and local affiliates. I have also presented lectures at New York University, Northwestern University, and the GLMA: Health Professionals Advancing LGBTQ+ Equality national conference. I currently serve on the board of directors for Fenway Health, as well as the Policy & Government Affairs Committee for GLMA ([GLMA, n.d.](#)).

## Conclusion

My experiences can provide valuable lessons for other nurses, advocates, and researchers. People want to see change, and they care about issues. Word of mouth is powerful, and the public trusts nurses. This has not been easy, but it has been worth it, and it has been fulfilling. This work has enabled me to impact the lives of thousands of patients, more than I could with a lifetime at the bedside. In this process, however, I have also lost a great deal of privacy and the ability to come out on my own terms. My online identity may permanently be tied to articles advertising the bisexual nursing student who fights for blood donor equality. It is important to be aware of potential emotional fallout.

Although my education helped me immensely, creating Pride and Plasma did not require a degree nor specialty training. Anyone can advocate; any nurse who cares deeply enough, can change healthcare. I used my interests to drive and motivate after dozens of “no’s” and non-replies. Advocacy is a core component of nursing, included in provision 3 of the American Nurses Association ([\[ANA\], 2015](#)) Code of Ethics for Nurses with Interpretive Statements. Health policy is included in provisions 7 and 9.

If you want to make a change, identify an issue. Determine who has the power to change it; who enforces it; and who is impacted by it. Reach out to these interested parties; send emails, letters, and direct messages. Identify who you will target with your advocacy (i.e., groups and individuals with the power to make change). Work with those who have a platform, such as nursing organizations, alumni associations, and members of the media, to spread the word. Find a way to gauge support

and to show the power behind your movement. This may include providing testimony, writing a petition, or providing public comments. Use the stories of those impacted to keep you going, researching, and mobilizing, even when you are told “no.” Never be afraid to ask for help or to seek advice. Keep fighting for a healthcare system that your patients, facilities, and coworkers deserve. Nurses are the ones at the bedside, talking to patients, and assessing the issues at hand. We should be the ones at the table proposing and speaking about solutions.

Creating an organization is as easy as building a team. Here are a few specific strategies to get you started:

- Find inspiration from individuals who work on similar or related issues. Look at who initiated action on previous efforts. Ask for their input.
- Draft a mission statement to share what do you want to do and why.
- Create a step-by-step plan to make progress easy to define and easier to accomplish.
- Identify related issues that can be tackled by your current framework and methodology in order to continue good work after your initial and subsequent success.
- Ask for help, reach out to potential contacts, and work with those who are affected by the issue at hand.

Creating an organization to address a policy for which you have strong feelings can have a profound impact on your community and patient population. However, efforts of that scale are not required to make change. Smaller actions can include serving on hospital committees addressing issues like workplace violence, safe discharge, patient experience, and nursing innovation. Additional opportunities include:

- Joining your state or national nursing organizations (e.g., state affiliate of ANA and ANA). In addition, you may want to join other specialty professional nursing organizations.
- Provide testimony and advocacy when health legislation is on the docket in the legislature. Keep an eye on trends in other states; if you see something of concern or worth discussion in a different location, bring it up with your elected officials.
- Conduct your own research, work with your employer, alma mater, or colleagues to draft evidence-based solutions.
- Stay in the loop by following and engaging with nursing accounts on social media and through newsletters.
- Listen to and talk to your patients about what is directly impacting them and affecting their ability to live healthy lives to the fullest.
- Use your voice to uplift others and use your identity as a nurse to open doors to which the public may not have access.

You can do incredible, life-changing things if you just give it a shot! You can continue to impact lives through advocacy, even those across the country, with your words, work, and care.

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Cole Williams is a registered nurse in Boston, MA, where he works as a med-surg nurse at Tufts Medical Center. While completing his degree at the University of Cincinnati, he founded Pride and Plasma, an organization devoted to fighting for LGBTQ+ equality in blood, tissue, and organ donation. Cole's work and that of and Pride and Plasma, has been featured in the Washington Post, PBS Newshour, CBS News, Insider, local and international news affiliates. Cole currently serves on the Board of Directors at Fenway Health, and on the Policy & Government Affairs Committee for GLMA: Health Professionals Advancing LGBTQ+ Equality. Readers can find more about Pride and Plasma's work and join their fight at [prideandplasma.org](http://prideandplasma.org).

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