

**TO:** House of Representatives  
Commonwealth of Pennsylvania

**FROM:** Cheri Rinehart  
  
President & CEO,  
Pennsylvania Association of Community Health Centers

**DATE:** May 9, 2014

**RE:** Public Hearing HB 30 – Donate Life PA

Chairman Cutler, Chairman White and members of the committee,

Thank you for inviting me here today to speak to you about a very important subject, House Bill 30 and organ donation.

In my experience as a registered nurse and former vice president of The Hospital & Healthsystem Association of Pennsylvania, where one of my areas of responsibility was organ and tissue donation policy, HB 30 is vital to reasserting Pennsylvania as a leader in developing clinical best practices and improving awareness and education.

During my tenure at HAP, in collaboration with representatives of hospitals, coroners, OPOs, eye and tissue banks, donor families, and others, I facilitated the development of a standard Pennsylvania guide for hospitals on organ and tissue donation. We found that one of the major impediments to hospital support of organ and tissue donation was a lack of clear guidance on hospital roles and responsibilities, as well as policies and procedures.

A second impediment was rushed hospital staff and varying degrees of education, training, comfort and skill in offering the donation option to families. That, coupled with research that validates the importance of decoupling the pronouncement of death from offering the opportunity to donate, led HAP to support the change from “required request” to “routine referral”.

The change meant families would be approached by professionals trained to have this conversation in a sensitive and informed way, rather than by hospital staff.

The move to routine referral was initially met with resistance by some physicians and hospitals, but experience showed that it was more effective and resulted in better outcomes and there are likely few individuals today who would prefer to return to the former process. The new process better meets the needs of loved ones of the deceased, recognizes and respects the needs of the different stakeholders and optimizes outcomes through collaboration.

By optimizing outcomes, I don’t simply mean an increase in the number of consents for donation or the number of organs and tissues available for donation, but also that families, hospital staff and organ and tissue procurement staff all feel positive about the experience and that the results reflect as much as possible what the deceased wanted.

Based on my prior experience and the fact that 43 other states have implemented similar changes to their Uniform Anatomical Gift Acts with positive results, I believe that much of the remaining concern about HB 30 is based on fear and resistance to change and that implementation will prove that you did the right thing in supporting and enacting the bill.

I also believe based on my experience that individuals who make a donation decision for themselves as well as hospitals and health systems will welcome the clarity the legislation gives on that decision and that first person authorization for donation will be honored.

I have made my donation decision and I would not want anyone without just cause to have the authority to override that decision when I am no longer able to speak for myself. I have spoken to many individuals who were shocked and bothered that family or others could override the personal donation decision they had made.

I have had the opportunity through my involvement with organ and tissue donation for more than two decades to speak to many loved ones of individuals who were able to give the gift of life as well as those who were denied that opportunity.

It is a rare family member whose loved one was able to give the gift of life through their death who fails to get some comfort from that fact. On the other hand, those who were denied that opportunity for whatever reason are often angry because their sense of grief and the impact of the loss of their loved one were compounded by that missed opportunity.

It is never easy for families, but it is always easier to make the decision if they know they are following the wishes of their loved one. That is one of the reasons that the education and registry components of the bill are so important – whenever possible, we want individuals to make informed donation decisions for themselves.

For example, many of the more than 700,000 individuals served by the community health centers I represent as president and CEO of the Pennsylvania Association of Community Health Centers have either not made a donation decision or have chosen not to be a donor because of rumors and falsehoods that have been perpetuated in their communities – sometimes for generations. It will be great if we can break this chain of misinformation so the next generation can make decisions informed by fact and in advance of catastrophe.

HB 30 extends the educational initiatives regarding donation and transplantation in current law to include all high schools in the commonwealth. States such as Iowa (67%) and Ohio (55%) that require some form of organ donation education in their high schools lead the nation in donor designation rates. Pennsylvania's designation rate currently stands at 45%.

Another barrier we faced in the past and continue to face to a lesser extent is that health professionals themselves – who individuals often rely on for advice whether they are neighbors, friends or caregivers – have not in their educational experience received information on organ and tissue donation. This is an important education gap to fill if people are to make informed decisions with regard to organ and tissue donation.

In summary, HB 30 is vital to improving the organ and tissue donation process in Pennsylvania hospitals and will increase designations to the rates currently experienced in other states by educating the public.

The bill will streamline the process and make it more uniform for all hospitals across the commonwealth and will give hospital more direction in regards to the donation process.

These improvements to Pennsylvania law, among the many others within HB 30, will also reinstate our commonwealth as a national leader in the number of life-saving donations and transplants that we facilitate.