

Statement of Mark S. Singel  
Organ Donation Fund

House Majority Policy Committee  
Hon. Kerry Benninghoff, Chair

Thursday, April 9, 2015

Chairman Benninghoff and Members of the Committee:

It was kind of you to invite me to make some remarks about the Governor Robert P. Casey Memorial Organ and Tissue Donation Fund and on organ donations in general. One of the benefits of longevity in and around the political process is that sometimes you watch legislative seeds sprout into good public policy.

In addition to Governor Robert P. Casey who provided a focus and the impetus for legislation with his own dramatic heart-and-liver transplant, it would be appropriate for us all to take a moment and thank William Michael Lucas and his family. Michael, a 34-year-old murder victim from Monessen literally gave the gift of life to Pennsylvania's Governor in June of 1993. In that same month, one of my first acts as Acting Governor was to sign my own organ donation card and to kick off an aggressive campaign to encourage more organ donations. Several legislative initiatives were introduced, discussed, and amended.

It was Governor Casey himself who signed Act 102 into law as one of his final acts as Governor. That law, which requires hospitals to report organ donor candidates to appropriate organ procurement organizations, enabled organ donations to double over time; tissue donations have tripled. That law also became the model for legislation across the country and, in 1998, was adopted by the CMS as the federal standard for organ and tissue donations. What this means is that organ donors, together with hospitals, medical professionals, and compassionate governmental leaders have saved thousands upon thousands of lives in Pennsylvania and throughout the nation.

The most recent report from the Organ Donation Advisory Committee notes that the fund established by Act 102 has about \$2.4 million. The money comes from optional donations when registering a vehicle or obtaining a driver's license; optional check-off on state income tax returns, and private donations. It is allocated by law for donor awareness programs and educational initiatives at the secondary level.

Organ donations save lives. More organ donations will save more lives. Recent reports show that there are about 8,500 patients waiting for an organ transplant in Pennsylvania. Therefore it is necessary to review the progress of organ donations and to adjust the language of Act 102 to meet current needs.

Like every issue, amending Act 102 will be subject to a number of perspectives. I respect that discourse and look forward to healthy debate on some key issues. Since you were kind enough to invite me here, however, let me suggest four areas that need to be addressed:

1. Funds for funerals and family bereavement. The original bill provided 10% of the trust fund monies should be allocated to donor expenses including funeral costs, hospital expenses,

and counseling for families. The amount was limited to \$3,000 per donor family. This provision was abandoned by the PA Department of Health for fear of violating federal statutes against the buying and selling of organs. Incredibly, the families of Michael Lucas and others who give the gift of life are left only with their own pain when organ donations are made by a loved one. There is no way a reasonable person could construe a nominal donation for funeral expenses as organ trafficking. Governor Wolf can and should promulgate regulations to correct this injustice.

2. Criminal justice proceedings. Coroners and their medical examiners have a legitimate interest in preserving evidence in certain cases. On the other hand, organ recovery is clearly time-sensitive. I am advised by medical professionals that organ recoveries rarely hamper autopsies for forensic pathologists. In fact, those pathologists involved with organ recovery are sometimes asked to conduct the autopsy simultaneously. This assures that organs remain vital, but respects the rights of coroners and their medical staffs. I agree with the suggestion that coroners or their designee should weigh in by consulting the medical team in the operating room to determine what, if any, reason would exist for not proceeding.
3. Disease testing. Since the law was enacted, there have been advancements in technology that make testing for infectious diseases more effective. Additional resources should be allocated for enhanced testing of the range of diseases that could complicate organ donations.
4. Community education. More resources from the fund should be allocated though the Department of Health for education at the community level. More people should be aware of the success of Act 102 and be encouraged to sign up as donors.

Thank you, Mr. Chairman for letting me make these suggestions. And thank you for your leadership in making a good law better.