Statement of the Pennsylvania Catholic Conference and the Pennsylvania Catholic Health Association on House Bill 30 - Donate Life PA

PRESENTED TO

THE HOUSE JUDICIARY COMMITTEE

SUBCOMMITTEE ON FAMILY LAW

By

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PENNSYLVANIA CATHOLIC HEALTH ASSOCIATION

MAY 13, 2014

Good morning Mr. Chairman and members of the Subcommittee.

I am Richard Connell, a partner in the Harrisburg area law firm, Ball, Murren & Connell, which serves as legal counsel to the Pennsylvania Catholic Conference (PCC) and the Pennsylvania Catholic Health Association (PCHA). With me is Sister Clare Christi Schiefer who is a member of the PCC staff and is President of PCHA. For your information, Sister Clare, in the past, served as a member of the Department of Health Advisory Committee on Organ and Tissue Donation during the term of former Secretary of Health, Dr. H. Arnold Muller.

PCC is the public affairs arm of the Catholic Bishops of Pennsylvania which represents the eight Latin Rite Dioceses of Pennsylvania and the two Byzantine Rite Catholic Dioceses whose territories include the Commonwealth of Pennsylvania.

The Pennsylvania Catholic Health Association is a statewide organization composed of Catholic health care facilities and other individuals and groups which promotes the integrated Catholic health care ministry in Pennsylvania.

Before presenting testimony, I note that our remarks are principally directed to Senate Bill 850, Printer's Number 1593. While this hearing is about House Bill 30, Printer' s Number 2125, Sr. Clare and I learned during a recent meeting with Representative Petrarca (the prime sponsor of House Bill 30) that House Bill 30 is expected to be changed to be very much like Senate Bill 850 (P.N. 1593). The original version of Senate Bill 850 (P.N. 933) had been commented upon for PCHA/PCC on June 7, 2013. (See Memorandum to Gregg L. Warner, Esq., of Senator Greenleaf's staff – Attachment "A".) Thereafter, Sister Clare and I met with representatives of organ procurement organizations. Subsequently, the Senate Judiciary

Committee on November 19, 2013 amended the original printer's number of Senate Bill 850. On December 3, 2013, a new Memorandum was prepared and was subsequently submitted to Mr. Warner on behalf of PCC/PCHA and is attached as Attachment "B". The observations and concerns set forth in that memorandum remain open for PCC/PCHA and should be considered part of the testimony today. Some of those matters and others will be discussed later.

Organ donation is, in Catholic moral tradition, based upon informed consent which is the "stipulation that an organ donor must explicitly consent to the donation prior to organ procurement, and informed consent is a necessary component of the Church's teaching on the morality of organ donation and transplantation for two reasons. First, informed consent affirms and protects the intrinsic dignity and inviolability of the human person. Next, informed consent respects the essential formality of the donated organ as a gift that one person gives to another".[1]

Father Austriaco, who wrote the cited article, is quoted here at length because he so well captures the Church's position. He notes:

> "Since the time of Pope Pius XII, the Catholic Church has explicitly supported the procurement of organs... For the Catholic moral tradition, organ donation is justified by the principle of charity. The person who donates an organ to a patient is making a genuine act of sacrifice modeled after the Lord's sacrifice of himself on the cross. ... Organ donation is an act of self – gift of the human person. As [recently canonized Saint] John Paul II emphasized... "Every organ transplant has its source in a decision of great ethical value: the decision to offer

[1]"Presumed Consent for Organ Procurement", Rev. Nicanor Pier Giorgio Austriaco, O.P., The National Catholic Bioethics Quarterly, Vol. 9, Number 2, p.p. 245, 246. (2009)

without reward a part of another person. Here precisely lies the nobility of the gesture, a gesture which is a genuine act of love."[2]

And it is to be understood that the Catechism of the Catholic Church teaches: "organ donation upon death is a noble and meritorious act and is to be encouraged as an expression of generous solidarity." (Catechism of the Catholic Church, 2nd ed. Trans, U.S. Conference of Catholic Bishops, n. 2296.)

To understand the Church's view of organ donation, it is also important to know that the "Ethical and Religious Directives for Catholic Health Services" issued by the United States Conference of Catholic Bishops, provide that:

> "Catholic health care institutions should encourage and provide the means whereby those who wish to do so may arrange for the donation of their organs and bodily tissue, for ethically legitimate purposes so that they may be used for donation and research after death."[3]

The Catholic Church in Pennsylvania is no stranger to the issue of organ donation. In 1995, the Pennsylvania Conference on Interchurch Cooperation – a statewide ecumenical organization representing Anglican, Orthodox, Protestant and Roman Catholic church bodies in Pennsylvania – joined "in urging the people of the Commonwealth to share the gift of life through donations of organs, tissues and blood." These church groups urged "the members of the Christian community to lead the way by talking to people and their families, congregations

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[2] Ibid. 247

[3] Ethical and Religious Directives For Catholic Health Care Services, Fifth Edition, United States Conference of Catholic Bishops, Washington, D.C. (2009)

and communities about the possibility of donating organs and tissue. We ask pastors and other church leaders to encourage it in their parishes and congregations."[4]

In considering Senate Bill 850 and House Bill 30, PCC/PCHA have turned to the PCHA Board which includes hospital CEOs, long-term care facility representatives and the lead ethicist from a major national Catholic health care system. These members have provided wonderful insight into the organ procurement process and have affirmed the especially laudable informed consent decisions to donate organs. In addition, PCC/PCHA have turned to Dr. Marie T. Hilliard, MS (Maternal Child Health Nursing), MA (Religious Studies), JCL (Canon Lawyer), Ph.D., R.N., Director of Bioethics and Public Policy, The National Catholic Bioethics Center, Philadelphia, PA.[5] Dr. Hilliard's comments about the subject legislation are incorporated below in our testimony which focuses on some of the areas noted in Attachments "A" and "B".

The focus of testimony today relates primarily to: the list of those authorized to consent to an anatomical gift; how that list is used; whether presumed consent is, in effect, created; the effectiveness of a revocation of a gift; and the possible invocation of foreign laws. To the extent that issues set forth in Attachment "B" are not specifically discussed today, please know that those concerns remain.

The bill provides that coroners or medical examiners, wardens of correctional facilities where a decedent was incarcerated, an administrator of a social service agency having a relationship with a decedent, a person that exhibited special care and concern for the decedent

[4] "Sharing the Gift of Life: A Pleas for Organ Donations", Pennsylvania Conference on Interchurch Cooperation, Harrisburg, PA (1995) Sister Clare was instrumental in influencing formulation of this ecumenical statement.
[5] The National Catholic Bioethics Center is a non-profit research and educational institute committed to applying the moral teachings of the Catholic Church to ethical issues arising in health care and the life sciences.

or a hospital administrator can donate all or any part of a decedent's body. While clearly intended to expand the number of potential harvesting of organs, the group seems unlikely to produce any informed consent. Instead, by conferring the power to make gifts to such individuals, there is, in our view, the creation of presumed consent. Such persons with authority may simply see "donation" as a duty requiring little thought and reflection. But, for the decedent from whom the organs would be taken, he or she will have no advocate and no balance. Effectively, the "donors" could include the poorest of the poor and the most outcast. By creating this authority, the state, in effect, moves away from informed consent.

Some concern arises as it relates to limited liability for a person under Section 8616(c). While current law provides limited immunity for acting in accordance with the anatomical gift laws of another country, the status of anatomical gift laws has changed significantly over the years. In Europe, for example, the standard now is presumed consent. Does this part then mean that immunity is conferred even if the person acts in a manner inconsistent with Pennsylvania law? That does not seem desirable.

Another area to consider is that which deals with the effectiveness of a revocation. Under Section 8615(d), a revocation takes effect before an incision has been made to remove an organ and before invasive procedures have begun for the recipient. There is a balancing here, but if an attempt to revoke is made, it should be observed that an incision can be reversed. Also, as to a recipient (who, it is noted, has much at stake and has been prepared for a transplant), if the invasive procedure is a venous line, should that act alone preclude an effective revocation?

Doctor Hilliard noted a concern about the procedure to be followed by hospitals which would require notification of the organ procurement organization that death is imminent. She advised that the National Catholic Bioethics Center had secured an agreement by the Organ Procurement and Transplantation Network in its Non-heart Beating Death Protocol that none of the procedure can occur until the family has decided to remove life support. Such a step seems advisable here as well.

Under the bill, hospitals are precluded from withdrawing or withholding measures necessary to maintain medical suitability. Doctor Hilliard in her review noted that, with respect to that section 8617(d)(2), the National Catholic Bioethics Center had negotiated with and achieved agreed-upon language with the National Conference of Commissioners on Uniform State Laws in November, 2009. That language is set forth as Section 14(c) on Attachment "C".

A final observation is that Section 8617(f.2) could be improved by adding: "No recovery personnel (surgeons or other practitioners) may be present for the withdrawal of life-sustaining treatment or ventilated support."

Please know that careful attention to the concerns raised and issues identified is appreciated. As stated earlier, the Catholic Church has long advocated for and encouraged organ donation. That advocacy is based upon a donative spirit, informed consent and respect for the dignity of the person. These bases are the foundation upon which the Catholic Church evaluates such well-intended legislation.

On behalf of the Pennsylvania Catholic Conference and the Pennsylvania Catholic Health Association, thank you for your attentiveness.

For the Pennsylvania Catholic Conference and the
Pennsylvania Catholic Health Association

Richard E. Connell

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ATTACHMENT A

Attachment "A"

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WILLIAM BENTLEY BALL
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MEMORANDUM TO: Gregg L. Warner, Esq.

FROM: Richard E. Connell, Esq.

DATE: June 7, 2013

RE: Anatomical Gifts – Senate Bill 850 (P.N. 933)

Thank you for meeting with Sr. Clare and me on June 3. Among the matters we discussed was Senate Bill 850 (P.N. 933) introduced by Senator Greenleaf. As Sister Clare had noted to you last session, the Pennsylvania Catholic Conference (PCC) and the Pennsylvania Catholic Health Association (PCHA) had concerns about Senate Bill 100 and House Bill 750. While the approach used in this session's Senate Bill 850 is different, there are some areas which, it is believed, need some attention. Below are some observations about the bill.

- For clarification, the definition of "prospective donor" eliminated the following language used in Senate Bill 100:

  "... term does not include an individual who made a refusal."

  Is that simply because the bill this session does not include a refusal clause as had Senate Bill 100 of last session?

- The definition "person authorized or obligated to dispose of decedent's body" includes:

  Administrator or authorized official of a social service agency having a relationship with the decedent (Page 4, lines 7-8).

  What does that mean? A food pantry? A homeless shelter? A counseling service? Or is it a more specific relationship? While there may be times when a

social service agency is the only advocate for a person, the definition is very broad and does not suggest a confidential relationship of any type nor any requirement that the person be well-known to the agency administrator.

- People other than the patient who can donate are those "reasonably available" and "able and willing". (Page 5, lines 26-29) What do these terms mean? How much effort is required to determine if a person is "reasonably available"? If a person in a class is "unwilling" (and is known to be so) but is not "reasonably available", it appears the consent can be obtained at the next level. Is that appropriate?

- An agent includes "an individual expressly authorized to make an anatomical gift on another's behalf; by any other record signed by the individual giving authorization" (Page 2, lines 15-17). A clarification is needed. There seems to be an internal inconsistency. It appears to say that the person acting for the patient is the one who grants himself/herself authority to make the gift for the other person

- A person who can make a gift includes "a person that exhibited special care and concern for the decedent (Page 7, lines 4-5). This is standardless. It could be a hairdresser or college buddy. Who will measure this?

- "A person authorized or obligated to dispose of the decedent's body" is authorized to make a "gift" (Page 7, lines 7-8). It is highly unlikely that a person at this level can reliably make a decision. Why should the "gift" be made by one with whom the decedent had no relationship? This seems to suggest the notion that organs and tissue should presumptively be taken without regard to a "donation".

- Page 7, lines 9-12, imposes an <u>obligation</u> upon a hospital administrator to "give" all or part of a decedent's body. This constitutes the only <u>mandated</u> "donor". But how is it a donation? Indeed, it seems to actualize what was set forth in SB 100 and HB 750 of the 2011 session, that is, to act "in favor of donation and the numerous potential recipients of anatomical gifts."

  It seems an administrator would not be able to consider the decedent's religious beliefs or moral convictions and could refuse only if there was a <u>known</u> objection. If a hospital had any policy or moral or religious reservations, it could not, it seems, avoid the mandate.

  And, if a section like this is to be included at all, it would need to be made clear that an administrator would be involved only after the list of prospective "donees" has been exhausted. As written, when the obligation to "give" is triggered remains to be seen.

- Page 8, line 30 and Page 9, lines 1-4 provide that if a person designates a donee but the transplant cannot occur, the part shall pass for other purposes unless there is a known objection. The donor loses control and

  effectively the presumption is that a donation for a specific, but unfulfilled purpose, becomes a donation for all purposes.

- Page 9, lines 19-25. This section deals with a donation for multiple purposes without a priority. If that occurs, the presumed priority is for transplant/therapy (as written, it seems, even if transplant/therapy are not listed as a purpose by the donor). If the part cannot be used, then it may be used for research/education.

  If the multiple purposes are only research/education without a priority, does the section require use for transplant/therapy?

  Some clarification may be needed.

- Page 12, lines 25-30, the section provides that withdrawal of consent cannot occur after an incision has been made or after "invasive procedures" (undefined) have begun. But does that make sense? An incision can be reversed and if consent is withdrawn should that not be the end of it?

- Page 13, lines 1-7 provides that a revocation under this law does not constitute a known refusal and therefore a "donation" can still occur. This continues the sense that this is less about donation and more about taking.

- Page 21, lines 26-29. While a physician who certifies death cannot participate in a transplant, his/her partners would not be precluded. Should the ban be extended to partners as well?

- Under current law, organ donor protocols would be required to "take into account the deceased individual's religious beliefs or nonsuitability for organ and tissue donation."

  No such requirement is in the proposed legislation.

- The bill at page 19, lines 22-28, requires that a hospital administrator, among other things, must record the name of the person who refused to make a gift. To whom will such information be made available? Why? Will the identity be shared in a way that subjects that person to later inquiry or contact about the refusal?

- The procedure for testing for suitability prevents a hospital from withdrawing or withholding any measure necessary to maintain the suitability of the

organs/tissues. Page 20, lines 20-23. This is not about patient care. It is without regard to the patient. This ignores contrary intent by the patient. And it ignores that it may do harm to the patient or in fact cause death by other than the underlying pathology.

- Pages 37 and 38 deal with circumstances of conflict between an advance directive and a "gift". The bill provides that the gift will occur and that treatments will be withdrawn or withheld even if directed otherwise in the advance directive. Language should be added to assure that the advance directive will control.

There may be other areas of concern which will be developed as PCC and PCHA continue review of this bill. It is important to note that the Church has long advocated organ donation. But that advocacy is based upon giving and respect for the dignity of the person. It is with that foundation that the Church evaluates legislation like this.

Please let Sister Clare know if any additional information is needed.

BALL, MURREN & CONNELL

BY: *Richard E. Connell*
Richard E. Connell

REC/gjc

ATTACHMENT B

Attachment "B"

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WILLIAM BENTLEY BALL
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MEMORANDUM TO:	Sr. Clare Christi Schiefer, OSF
FROM:	Richard E. Connell, Esq.
DATE:	December 3, 2013
RE:	Senate Bill 850 (P.N. 1593)(P.P.N. 933) (Greenleaf)

The major changes to the organ donor bill include the elimination of the mandatory language which would have required a hospital administrator to make an organ donation (Page 7, lines 1-18); the addition of language which encourages sensitivity to family circumstances and takes into account the deceased individual's religious beliefs in organ procurement protocols (Page 20, lines 16-21); and a clarification about multiple purpose gifts (Page 9, lines 28-29 and Page 10, lines 2-3).

The new refusal provision seems to recognize that people should be able to decide to refrain from making anatomical gifts (Page 13, lines 4-11). But most people are unlikely to realize that they need to make a written statement to prevent organ taking. Inaction is tantamount to presumed consent.

PCC/PCHA concerns about revocation of a gift after an incision has been made were addressed (Pages 13 and 14), as were concerns about reporting the name of an individual who would refuse to consent to an anatomical gift (Page 20, line 28).

There are other points which PCC/PCHA have previously raised some of which were not changed or adequately addressed.

- PCC/PCHA had noted concern about the definition "person authorized or obligated to dispose of a decedent's body" as it listed "an administrator or authorized official of a social service agency having a relationship with the decedent". The amended bill deletes the word "authorized" but does not otherwise address concerns expressed about this (Page 4, line 12).

PCC/PCHA had questioned whether this meant a food pantry, a homeless shelter or a counseling service. The proponents noted that, statewide, authorization for a gift by such a person might occur once a year. It was explained that it would apply to any person who steps forward and has a relationship.

It might be improved by adding to the definition a requirement that the relationship would be "significant and continuing". Since this seems to be so seldom an occurrence, it might be better to eliminate this category entirely. If it is not eliminated, the decedent's organs become like a commodity, the disposition of which may be left to a virtual stranger.

- The definition of "reasonably available" has been changed slightly. The definition relates to contacting people to make an organ donation (Page 5, line 5). As amended, it seems to be sensitive to concerns expressed by PCC/PCHA.

- PCC/PCHA had expressed concerns that one part of the definition of the word "agent" was confusing. This is not addressed in the new Printers' Number. As written, subpart (2) (Page 6, lines 16-18) of the definition appears to say that the person acting for the patient is the one who grants himself authority to make a gift. It simply does not make sense.

- PCC/PCHA have previously noted that towards the end of a long list of people who can make an anatomical gift there is listed "a person that exhibited special care and concern for the decedent" (Page 7, lines 10-11).

  The proponents said that this is consistent with uniform law but it seems imprecise and open to possible abuse. No parameters as to time or nature of the relationship exist. Simply because organ donation is an important step should not lead to an atmosphere in which a decedent – especially one without an advocate – becomes a commodity or chattel.

  As written, such a person might include a grade school teacher, a high school coach, a college friend or a hairdresser. There are no limits as to the time during which special care and concern was exhibited nor of what character that care and concern would be. Who would evaluate this? The procurement organization? How could the evaluation be questioned or challenged?

- PCC/PCHA had also expressed concern about the last in the listing of potential donees, namely, "a person authorized or obligated to dispose of the decedent's body" (Page 7, lines 13-14).

  Proponents explained that this is current law. However, the category seems to reduce the person to property/chattel status and, it would seem, the body is just an asset to be claimed for the public good. Is this society's way of saying that

this poor soul had a shallow existence but at least something good can come of his/her worthless life?

- The bill refers to directed donations (Page 9, lines 6-10) but is unclear if a person designates an anatomical gift to an individual (Page 9, lines 1-3), but the gift cannot be transplanted into the designated individual (Page 9, lines 6-8), the part is to pass, it appears, for transplantation and therapy (Page 9, lines 11-12). But this does not seem to be based upon informed consent. Instead, it presumes that if a person wanted to give an anatomical gift to someone, he/she would want it to be used for other transplantation or therapy. This donative spirit is presumed by the bill but is such a presumption reasonably created? In effect, the government decides what will happen.

- The bill still does not require the list of people who can consent to a gift to consider the person's moral/religious beliefs before consenting to an anatomical gift. While the bill does require that the procurement protocol consider the "religious beliefs" of the decedent (Page 20, line 20), no obligation is imposed upon those who can consent to the gift. It seems that should occur and such an amendment would be consistent with the duties of a surrogate under the advance directive law.

It is unclear whether, as a practical matter, the requirements imposed on a hospital under the processes set forth at pages 21-23 present a problem. It is noteworthy that the section purporting to address issues with advance directives has been removed from the bill (Pages 39-40).

BALL, MURREN & CONNELL

BY: *Richard E. Connell*
Richard E. Connell

REC/gjc

ATTACHMENT C

ATTACHMENT "C"

UAGA Amendments Agreed Upon by the National Conference of Commissioners on Uniform State Laws and The National Catholic Bioethics Center.

November 3, 2009

Section 2 (4)

"'Decedent' means a deceased individual whose body or part is or may be the source of an anatomical gift. The term includes a stillborn infant and a fetus. The term 'fetus' does not include a blastocyst, embryo, or fetus that was the subject of an induced abortion."

Section 14 (c)

"(c) When a hospital refers an individual at or near death to a procurement organization, the organization may conduct any reasonable examination necessary to ensure the medical suitability of a part that is or could be subject of an anatomical gift for transplantation, therapy, research or education from a donor or prospective donor. During the examination period, measures necessary to ensure the medical suitability of the part may not be withdrawn unless the hospital or procurement organization knows that the individual expressed a contrary intent. Measures necessary to ensure the medical suitability of the part from a prospective donor may be administered unless it is determined that the administration of those measures would not provide the prospective donor with appropriate end-of-life care, or it can be anticipated by reasonable medical judgment that such measures would cause the prospective donor's death other than by the prospective donor's underlying pathology.

Section 21(b) revised

"(b) If a prospective donor has a declaration or advanced directive and the terms of the declaration or directive and the express or implied terms of a potential anatomical gift are in conflict with regard to the administration of measures necessary to ensure the medical suitability of a part for transplantation or therapy, the prospective donor's attending physician and prospective donor shall confer to resolve the conflict. If the prospective donor is incapable of resolving the conflict, an agent acting under the prospective donor's declaration or directive, or, if none or the agent is not reasonably available, another person authorized by law other than this [Act] to make health-care decisions on behalf of the prospective donor, shall act for the donor to resolve the

conflict. Information relevant to the resolution of the conflict may be obtained from the appropriate procurement organization and any other person authorized to make an anatomical gift for the prospective donor under Section 9 of this [Act]. Before the resolution of the conflict, measures necessary to ensure the medical suitability of the part from a prospective donor may be administered unless it is determined that the administration of those measures would not provide the prospective donor appropriate end-of-life care, or it can be anticipated by reasonable medical judgment that such measures would cause the prospective donor's death other than by the prospective donor's underlying pathology. If the conflict is not resolved expeditiously, the direction of the declaration or advance directive controls."