

## Protect Grieving Families. Restore Trust.

### Support the *Consensual Donation and Research Integrity Act* (S.1270 / H.R.2589)

#### The Issue: Grieving Families Deserve Equal Protection

Every year, thousands of families make one of the most generous decisions imaginable: donating a loved one's organs to save lives or donating their body to advance medical research and education.

Families who donate organs for transplantation are protected by a comprehensive federal framework that ensures transparency, oversight and accountability. Families who donate a whole body for research and education are not. That disparity leaves grieving families vulnerable.

If you are a grieving spouse, parent or child, you should not be treated differently depending on the type of donation.

#### The Problem: A Dangerous Gap in Federal Oversight

While organ and tissue donation operate under strict federal oversight, there is currently no federal law — and few state laws — governing the process when a body is donated for use in medical research or education. As a result:

- There is no national registry or tracking system
- There are no uniform chain-of-custody standards
- There are no consistent requirements for informed consent
- There is limited accountability when bodies are mishandled or misused

Bodies donated in good faith have been:

- Dismembered and sold for profit
- Used in ways not disclosed to families
- Transported across state lines to avoid regulation
- Not returned to families as promised

When transparency is lacking, trust is damaged — not just for whole body donation programs, but in the entire donation system.

#### Why This Matters to Funeral Service and Grieving Families

Funeral directors are often the last professionals to serve a family before donation and the first to care for remains afterward. When donation systems fail:

- Families experience delayed release of remains.
- Embalming and funeral plans may be disrupted.
- Funeral directors must explain practices they did not control.
- Public trust in all forms of donation — including organ donation — is weakened.

Grieving families should never feel like second-class citizens because they chose research instead of transplantation.

Donation is donation. Generosity is generosity. Protections should be equal.

#### What the Consensual Donation and Research Integrity Act Does

This bipartisan legislation would:

- Require for-profit whole body donation programs to register with the U.S. Department of Health and Human Services (HHS)
- Establish enforceable chain-of-custody standards
- Require transparent, standardized informed consent
- Create labeling, packaging and shipment standards
- Ensure proper final disposition and return of remains to families
- Establish federal penalties for fraudulent or unethical practices

Importantly:

- The bill does not apply to the Organ Procurement and Transplantation Network.
- It does not regulate medical schools or programs that do not sell bodies for profit.
- It is budget neutral, funded through registration fees.

This is not about opposing donation. Donation saves lives, advances science and trains the next generation of physicians. The National Funeral Directors Association strongly supports ethical donation of all types.

This legislation is about ensuring:

- Families are fully informed.
- Donor intent is honored.
- Human remains are treated with dignity.
- Public trust in the entire donation system is preserved.

## Emerging Oversight Concerns in Organ Procurement

Recent Congressional hearings and federal investigations have raised serious concerns about transparency, accountability and clinical practices within some Organ Procurement Organizations (OPOs). These investigations revealed:

- Failures in donor screening
- Interference in determination of death processes
- Inadequate informed consent
- Financial and accountability concerns

While organ donation remains a life-saving and critical system, recent findings demonstrate why consistent oversight, transparency and accountability are essential to maintaining public trust.

The *Consensual Donation and Research Integrity Act* complements these broader oversight efforts by ensuring that all forms of donation operate under clear federal standards.

Public trust is fragile. When transparency fails anywhere in the donation system, confidence declines everywhere.

## The Ask

We respectfully urge you to:

- ✓ Support S.1270 / H.R.2589
- ✓ Cosponsor the *Consensual Donation and Research Integrity Act*
- ✓ Help ensure grieving families receive equal protections under federal law

When families give the final gift of donation, Congress should ensure that gift is handled with transparency, dignity and respect.

## Sponsors

Sen. Thom Tillis (R-NC); Sen. Chris Murphy (D-CT); Rep. Gus Bilirakis (R-FL); Rep. Lizzie Fletcher (R-TX)

## Committee Jurisdiction

Senate Health, Education, Labor, and Pensions Committee; House Committee on Energy and Commerce

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