Children's Cardiomyopathy Foundation™

A Cause for Today. A Cure for Tomorrow.

CCF at Transplant Ethics & Policy Conference

Smilow Research Center, NYU Langone Health | October 22, 2026 | New York, NY

40%
Of children with severe DCM receive a transplant or die from heart failure within two years of diagnosis

2.9%
Organ donations fell by 494 (2.9%) in 2025 compared with 2024

13.6%
Organ donation after brain death declined

11.3%
Increase in organ donations after circulatory death

KEY DISCUSSION POINTS

Federal Funding & Policy Requests

- *Organ shortages persist: Expanding donation after circulatory death (DCD) was identified as one strategy to increase organ availability.*
- *Ethical challenges in organ donation: Key concerns include determining the timing of death, obtaining consent, preparing for organ recovery and communicating with families who decline donation.*
- *Separation of clinical care and organ recovery: Separating patient care decisions from organ procurement activities aims to ensure that donation considerations do not influence end-of-life care or hasten death.*
- *Policy and funding changes: Proposed CMS reimbursement changes could create financial uncertainty for organ procurement organizations (OPOs) and affect funding for donor family bereavement support, outreach and remembrance programs.*
- *Xenotransplantation: Discussed as a potential strategy for reducing the organ shortage.*
- *Transplant policy and legislation: Discussions covered evolving national policy and oversight, including the Organ Procurement and Transplantation Network (OPTN), and implications for organ allocation and patient outcomes.*
- *Donation laws and consent: Potential updates to the Uniform Anatomical Gift Act and legal, ethical and social questions surrounding donation for transplantation, research and education.*
- *Donor family support and compassionate care: Recognizing donor families as essential stakeholders, with opportunities to strengthen communication, collaboration, trust and grief support throughout and after the donation process.*
- *Perfusion and donor management: Ethical considerations in donation after circulatory death, end-of-life decisions, organ-preservation techniques and maintaining public trust.*

CCF RESOURCES

CCF continues to follow developments in transplantation that may affect children with cardiomyopathy and their families. Explore these resources to learn more:

CCF-Funded Research Publications

Educational Video "Will I Need a Heart Transplant?" featuring CCF Chief Medical Advisor Dr. Joseph Rossano

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WHY THIS MATTERS TO CCF

Conference discussions reinforced the importance of keeping children with cardiomyopathy and their families in view as transplant policy, organ availability and emerging technologies evolve. The donor-family session was a particularly important reminder that the experiences and needs of donor families should be heard and included in transplantation discussions.



Transplant Ethics and Policy Conference



Ethics of Perfusion Strategies and Donor Management
Moderator: Brendan Parent, JD; Panelists: Andrew Flescher, PhD; Philip Sommer, MD; Anji Wall, MD, PhD, FACS

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