

## Expert guidance informs process for supporting grieving families

First ever Canadian guidelines for pediatric deceased donation published

**NOVEMBER 6, 2017 (OTTAWA)** – Canadian Guidelines for Controlled Pediatric Donation after Circulatory Determination of Death (pDCD) have recently been released. These guidelines were published today in the journal *Pediatric Critical Care Medicine*.

In the absence of any national or international guidelines specifically addressing pDCD, Canadian Blood Services launched an initiative as part of its role in clinical practice guideline development, and provided expertise, project management and funding. The guideline development team, led by Dr. Matthew Weiss, created and released rigorously developed national clinical practice guidelines specifically for this practice.

Dr. Weiss, a pediatric intensivist working at Centre mère-enfant Soleil du CHU de Québec – Université Laval and a medical director in organ donation with Transplant Quebec, was inspired to help drive this initiative by a tragic case where donation was not possible for a family at his hospital.

“It all started with a patient and a family I cared for in 2013. As it became obvious that the child was not going to survive her illness, the father asked if she could provide organs to help others in need.” Dr. Weiss explains. “At the time, we did not have the infrastructure or the expertise to support pediatric donation after circulatory death, and I was forced to say no. Witnessing the disappointment that family suffered being denied the opportunity to bring some sense to their loss through donation motivated me to work with Canadian Blood Services to develop these guidelines. The goal of everyone on our project team was to ensure access to this type of donation for children and their families across Canada.” Weiss adds. [READ MORE](#)

With funding from Canadian Blood Services, the project team included representatives from pediatric intensive care units and neonatal intensive care units across the country, along with the Canadian Pediatric Society, Canadian Blood Services, Canadian Society for Transplantation, Canadian Critical Care Society, and the Canadian Association of Critical Care Nurses, united to work on this initiative. It was a lengthy process that began in October 2014 involving broad stakeholder input from clinical experts within the organ donation community across Canada.

“Very few countries have pediatric specific guidelines, most use or integrate parts of the adult process when dealing with children. This initiative was in response to a need expressed by the critical care community. They were specifically interested in guidelines that would help inform their approach with families that were based on dealing with children and sensitive to the needs of grieving families, and having a donor family member review the guidelines was critically important,” says Amber Appleby, associate director of deceased donation at Canadian Blood Services.

For immediate release

Jennifer Woolfsmith, whose daughter Mackenzy donated her heart, kidneys and liver in 2012, brought the patient family perspective, providing valuable insight from a parents' point of view.

“This work will give families who are faced with this kind of tragedy more opportunity to choose organ donation, and that is so important to me,” says Jennifer. “Knowing my daughter continues to impact the world through donation brings me so much comfort. So, it truly was my honour to contribute by reviewing these guidelines with the hope of giving other parents this option to bring purpose and meaning to the experience of losing their child.”

In practice, these recommendations will offer the meaningful possibility of organ donation to many more families experiencing the loss of a child and lead to increased organ donation, providing hope to children waiting for life-saving transplants. The guidelines themselves may also serve as a model for future clinical practice guidelines in deceased donation. 3

**Quick facts (highlights):**

- The guidelines include 63 Good Practice Statements, 7 recommendations including ethics, consent and withdrawal of life-sustaining therapy, eligibility, death determination
- These guidelines are the first national level guidelines to focus exclusively on the pediatric aspects of DCD.
- In adults, DCD is the fastest growing form of organ donation, full implementation of pDCD in Canadian pediatric hospitals could substantially increase the number of potential donors and transplants
- Dr. Matthew Weiss is Medical Director – Organ Donation at Transplant Quebec. He is a pediatric intensivist working at Centre mère-enfant Soleil du CHU de Québec – Université Laval, where he also served as medical specialist coordinator in organ and tissue donation. Dr. Weiss is available for interviews.
- Dr. Sam Shemie, Medical Advisor, Deceased Donation for Canadian Blood Services is also available for interviews.

**Associated Links**

Read the [Summary Report](#) published in *Pediatric Critical Care Medicine* and the complete [Canadian guidelines for controlled pediatric donation after circulatory determination of death](#) published on Canadian Blood Services' professional education website.

For immediate release

### **About Canadian Blood Services**

Canadian Blood Services manages the national supply of blood, blood products and stem cells, and related services for all the provinces and territories (excluding Quebec). We operate an integrated, pan-Canadian service delivery model that includes leading an interprovincial system for organ donation and transplantation. Our national scope, infrastructure and governance make us unique in the Canadian healthcare landscape. Canadian Blood Services is regulated as a biologics manufacturer by Health Canada and primarily funded by the provincial and territorial ministries of health. Canadian Blood Services is a not-for-profit charitable organization.



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