

**OPTN Uterus Workgroup  
Meeting Minutes  
October 8, 2019**

**Conference Call  
Linda Cendales, MD, Chair**

## **Introduction**

The VCA Uterus Workgroup met via Citrix GoTo#### teleconference on 10/08/2019 to discuss the following agenda items:

1. Data Collection/Transplant Outcomes Project

The following is a summary of the Workgroup's discussions.

### **1. Data Collection/Transplant Outcomes Project**

This project is slated to go out for Public Comment in January 2020. The VCA Committee is seeking input from practitioners in the community on the question of what data elements should be collected on the children who are born of a mother who has received a uterine transplant. Additionally, the Committee is considering to what age of the child that data should be collected.

#### Summary of discussion:

One participant commented that the child is followed by a pediatrician, not OPTN.

Once the transplant recipient is ex-planted, it can be a burden to follow the patient.

One member expressed the opinion that the child should not be followed beyond one year of age.

There can be geographic challenges to collecting the data since patients and their families may relocate or lived away from where the transplant took place.

One participant asked why OPTN collects the weight of the baby, but not the length.

Another participant asked if OPTN should add a category on NICU hospitalization if it was required, aka complication at birth.

One participant suggested that a new data element could be "the manner of delivery", i.e., Caesarean versus natural delivery.

Data Governance staff advised the workgroup that they should look to collect the minimal amount of data called for, as it will all likely be mandated to comply with the standards of review checklist. The group should consider what their hypothesis for increasing data collection is.

The Chair reminded the workgroup that the focus of the project is on policy development as it relates to patient safety. She had recently returned from the International Society of VCA Conference in India. A representative from Sweden shared that their country is collecting data on the child through adulthood.

HRSA suggested that the Committee could consult with the National Transplant Pregnancy Registry in Philadelphia, PA, operated by Gift for Life. Their program is voluntary and data is collected for 2 years.

#### Next steps:

Results of the workgroup call will be shared with the full VCA Committee at its monthly meeting on October 9, 2019.