

# Palliative Care in Fetal Cardiac Care

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# Disclosures

- I have no financial relationships or conflicts of interest to disclose.



# Objectives

- Define “full-scope” pediatric palliative care (PPC).
- Identify indications for PPC involvement prenatally.
- Describe the roles PPC can play along the continuum of congenital heart disease care.

# Outline

- I. Defining palliative care
- II. Indications for palliative care involvement
- III. Palliative care integration in the CM Fetal Health Center
- IV. Case examples



# I. Defining Palliative Care



# What is Palliative Care?

Etymology:

- From the Latin *pallium* (cloak), *palliare* (to cover)
- Relief without necessarily providing a cure or ‘fix’.
- “To cure sometimes, to relieve often, to comfort always.”



<https://postalmuseum.si.edu/>



# What is Pediatric Palliative Care?

- WHO definition (1998):
- The **active total care** of the child's body, mind and spirit. It also involves giving support to the family.
- Aims to evaluate and alleviate a child's physical, psychological, and social distress.
  - My word: **"Holistic"**
- Begins **when illness is diagnosed**, and continues regardless of whether or not a child receives treatment directed at the disease.
  - **"Accompaniment"**
  - **"Goal-concordant"**
- Effective palliative care requires a broad multidisciplinary approach that includes the family and makes use of available community resources; it can be successfully implemented even if resources are limited.
  - **"Family-centered"**
  - **"Interdisciplinary"**
- It can be provided in tertiary care facilities, in community health centers, and even in children's homes.
  - **"Continuity"**

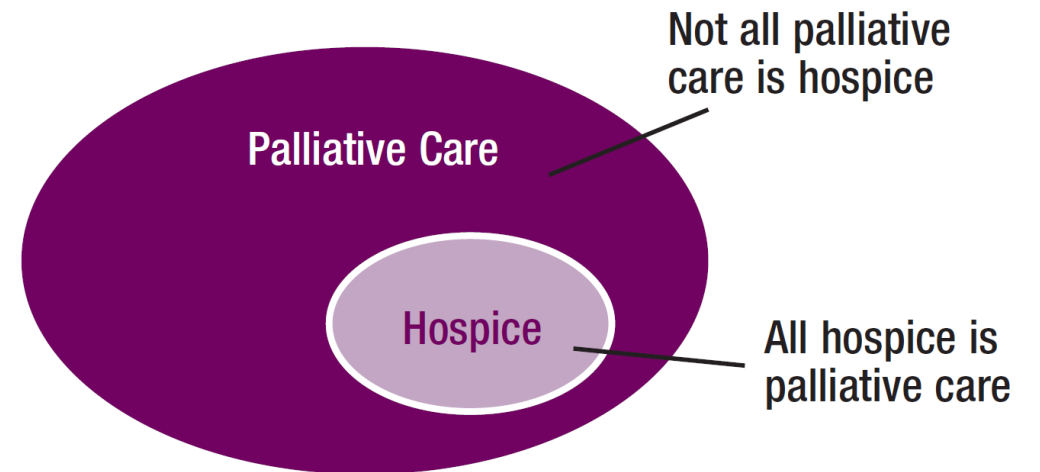


<https://www.chnola.org/>



# Common Misconceptions

- Palliative care ≠ giving up
- Palliative care is focused on improving quality of life and reducing suffering “upstream” for those with a serious illness.
- It’s about *living* well.
- Hospice is focused on comfort and dignity at the end of life.





# Palliative Care Roles

- Assessing goals of care
- Exploring conceptions of quality of life
- Supporting informed decision making
- Encouraging parallel planning
- Providing opportunities for advance care planning
- Working to relieve suffering and enhance quality of life
- Contributing to coordination of care



# II. Indications for Palliative Care Involvement



# Indications for Palliative Care Involvement



<https://www.facebook.com/tylershearteam/>

- Conditions for which curative treatment is possible but may fail.
- Conditions requiring intensive long-term treatment aimed at maintaining the quality of life.
- Progressive conditions in which treatment is exclusively palliative after diagnosis.
- Conditions involving severe, non-progressive disability, causing extreme vulnerability to health complications.



# CM PaCT “Trigger Consults”

- Fetal Health Center
  - Single Ventricle Congenital Heart Disease
  - Congenital Diaphragmatic Hernia
  - Trisomy 13, 18
  - Renal Agenesis
- ECMO
- Extreme Prematurity
- Heart Transplant Evaluation
- Oncology
  - Solid tumors with low survival rate
  - Relapsed cancers





The American College of  
Obstetricians and Gynecologists  
WOMEN'S HEALTH CARE PHYSICIANS

# ACOG COMMITTEE OPINION

Number 786

## Committee on Obstetric Practice Committee on Ethics

*The American Academy of Pediatrics and the Society for Maternal-Fetal Medicine endorse this document. This Committee Opinion was developed by the Committee on Obstetric Practice with the assistance of committee member Russell S. Miller, MD and the American Academy of Pediatrics' liaison member James J. Cummings, MD; and the Committee on Ethics with the assistance of the American Academy of Pediatrics' liaison member Robert Macauley, MD and the Society for Maternal-Fetal Medicine's liaison member Steven J. Ralston, MD, MPH.*

## Perinatal Palliative Care

- “With a dual focus on ameliorating suffering and honoring patient values, perinatal palliative care can be provided concurrently with life-prolonging treatment...”
- “Perinatal palliative comfort care is one of several options along a spectrum of care...that should be presented to pregnant patients faced with pregnancies complicated by life-limiting fetal conditions.”



# III. Palliative Care Integration in the CM FHC



# CM Fetal Health Center

- Mothers referred to FHC have an “integrated prenatal consult.”
- Certain diagnoses trigger involvement by our Palliative Care Team (PaCT).
  - Automatically or after multidisciplinary discussion.



# Palliative Care in the FHC

- PaCT typically meets families twice prenatally:
  - Integrated Consult
  - Follow-up PaCT/Neonatology consult
    - Opportunity to introduce a primary PaCT nurse





# Palliative Care in the FHC

- Integrated Consult
  - “Have you heard of palliative care before?”
  - “An extra layer of support from a medical angle...Complements the many available non-medical supports...”
  - “Accompany families navigating medical complexity and uncertainty...”
  - “A bridge from pre- to postnatal care...from unit to unit during the initial hospitalization...from one hospital stay to the next...”
  - “A neutral sounding board” for “exploratory conversations” about potential paths of care or about the “scary what-ifs.”
  - Acknowledgement of loss and grief



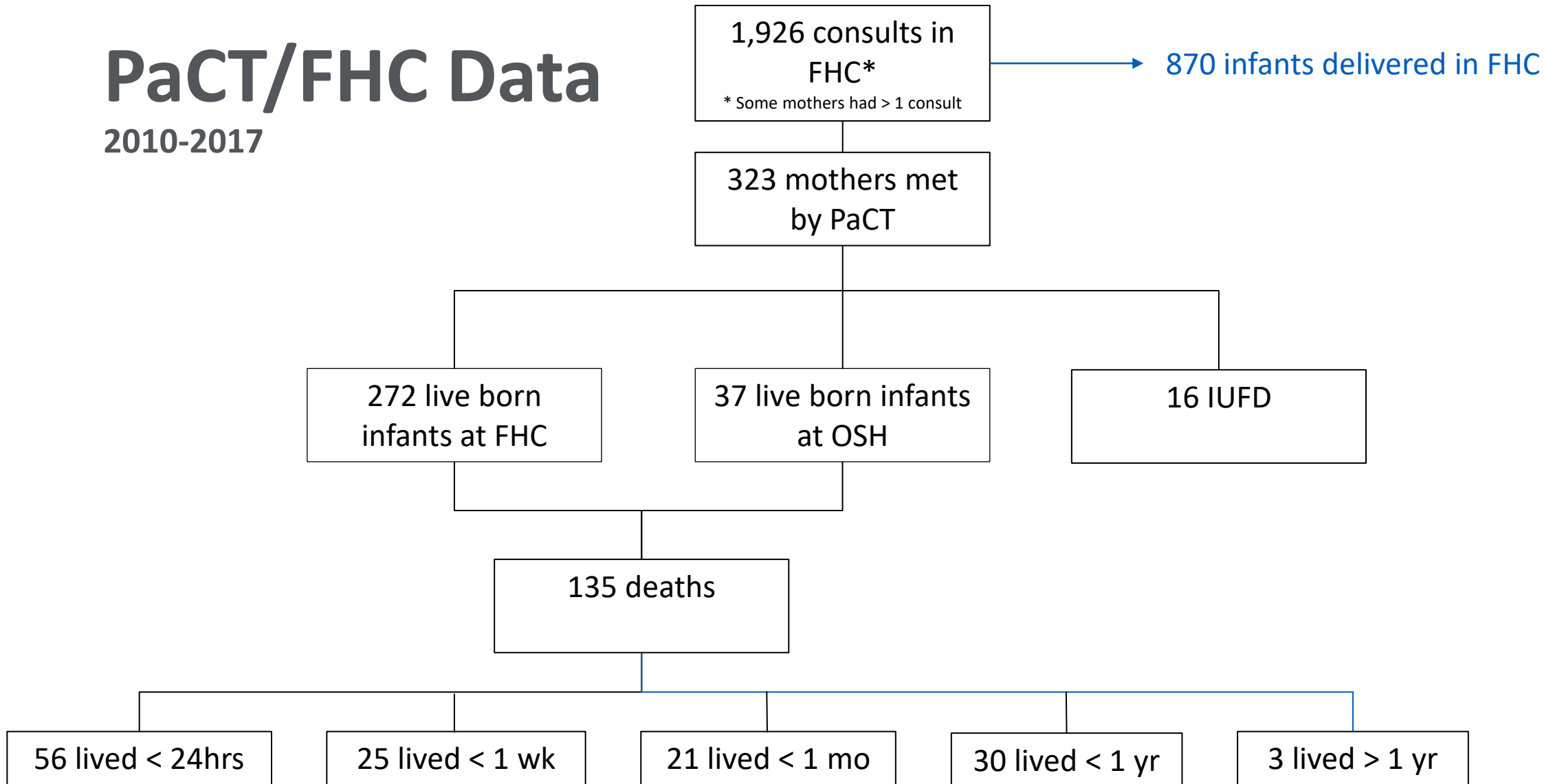
# Palliative Care in the FHC

- PaCT/Neo
  - Exploring parents' questions, concerns
  - Building rapport
  - Introducing a primary palliative care RN
  - Opportunity for decision making and advance care planning if needed

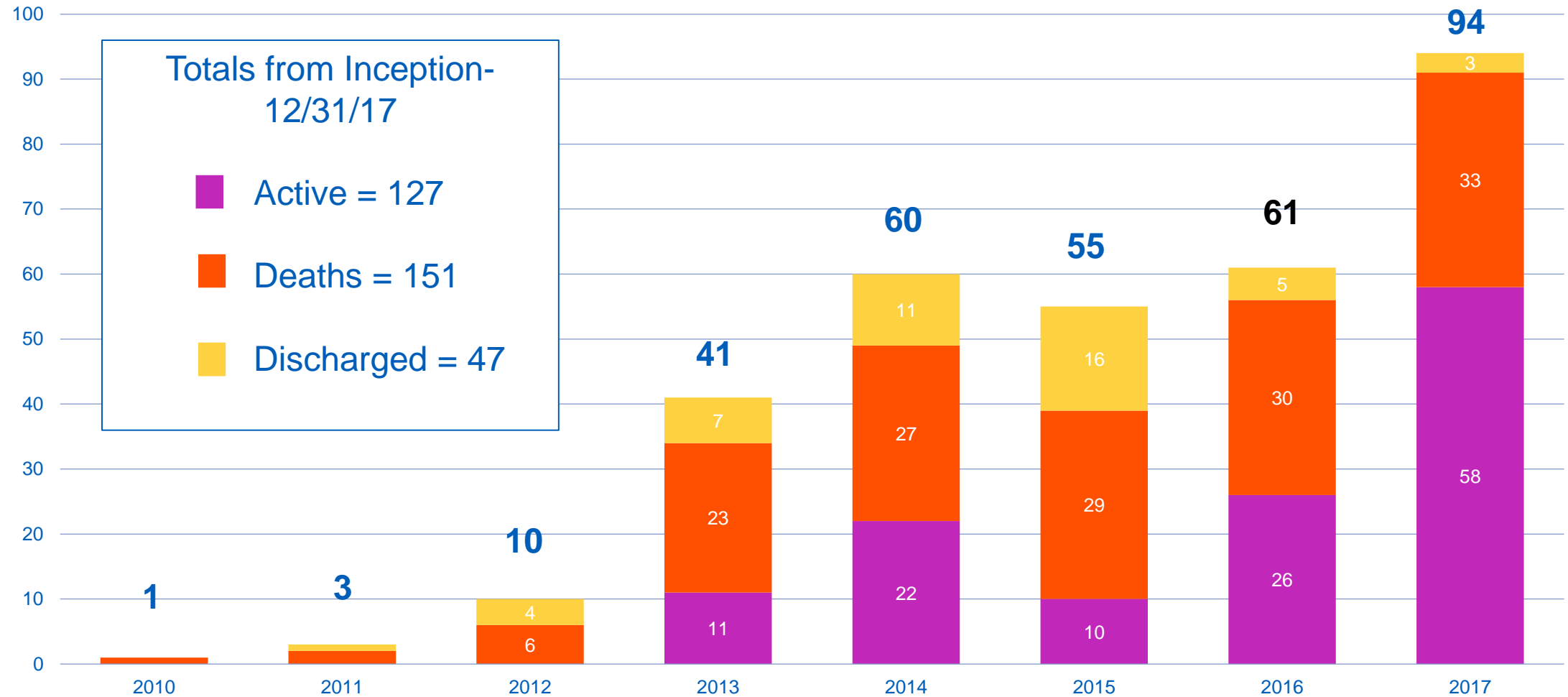


# PaCT/FHC Data

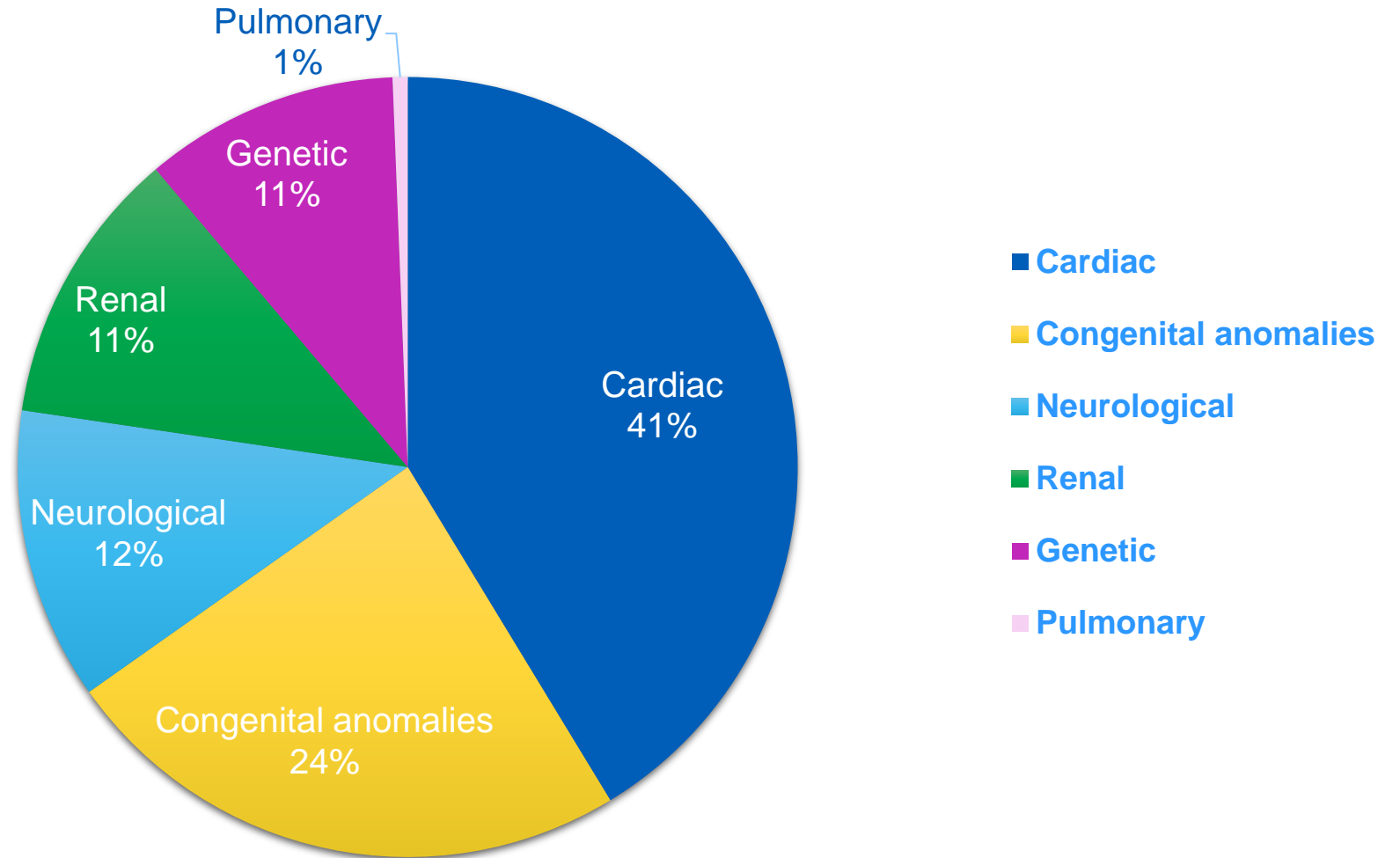
2010-2017



# Outcomes for PaCT FHC referrals



# FHC PaCT Referral Diagnoses



# IV. Case Examples



# CS

- Prenatal diagnosis of complex HRHS
- Parental desire to promote good QoL, protect from suffering, minimize regret
- After postnatal evaluation, recommendation for primary transplant
- Parents chose to forgo transplant listing and to take their daughter home for EOL care with hospice support.



# NK

- Late prenatal diagnosis of heterotaxy with concern for pulmonary venous anomalies and LVOT obstruction.
- Postnatal diagnoses of 2<sup>nd</sup> degree AV block and biliary atresia
- Failing Kasai, liver transplant recommended
- Parents initially chose NOT to pursue transplant due to cultural and religious beliefs and family experience
- After an eventful course, eventually did undergo transplant and is doing well





# IK

- Prenatal diagnosis of infantile myofibrillar myopathy with cardiomyopathy
- Older brother died of the same
- Parents desired comfort care and considered delivery in the FHC or closer to home in western Kansas
- Worked with Family Medicine physician and hospice team to plan for care at home



# EB

- Born at 28 weeks and diagnosed postnatally with HLHS
- Complex single ventricle course, including multiple ECMO runs
- “Graduated” from PaCT services following recovery from Fontan



# Acknowledgements

- Drs. Ellis, Linebarger, and Tucker for FHC/PaCT data and slides



# Thank you

- Questions?
- Comments?

