

# Pediatric Cardiac Technical Advisory Panel Annual Report Calendar Year 2023

SUBMITTED BY THE AGENCY FOR HEALTH CARE ADMINISTRATION

December 2023



**Better Health Care for All Floridians** 

### Introduction

Florida Statute section 395.1055 establishes the Pediatric Cardiac Technical Advisory Panel (PCTAP or "Panel") for Florida, provides direction to the panel, and requires the submission of an annual report to the Governor, the President of the Senate, and the Speaker of the House of Representatives beginning in January of 2020. As required in § 20.052, the Panel Chair and members hereby submit our fourth annual progress report on the activity and accomplishments of the Panel since inception in 2016 and through December 31, 2023.

#### History of the PCTAP

Various advocates for children and adults with congenital heart disease have long recognized the unique requirements for hospitals that perform complex invasive procedures in the treatment of often critical heart malformations. Such unique requirements embody criteria such as specialized fellowship training for the cardiac surgeon in congenital heart disease repair, cardiac perfusionists who can safely sustain a heart varying in size from a "walnut" to the standard adult heart intraoperatively, specialists in pediatric cardiac anesthesia, pediatric cardiac critical care, and nursing and respiratory staff who are familiar with the pre- and post-operative management of complex cardiac malformations. Standards for such a specialized system of care were developed and functioned successfully in the Division of Children's Medical Services (CMS) of the Department of Health (DOH) for over four decades. These standards were written by experts in pediatric cardiology and pediatric cardiac surgery and are revised every four years to keep pace with technological changes in the field.

#### **Enacting Legislation**

In 2017, the Florida Legislature enacted a new requirement for the Agency for Health Care Administration (Agency) to establish a pediatric cardiac technical advisory panel (PCTAP) to assist in the development of procedures and standards for measuring outcomes of pediatric cardiac catheterization and surgery programs; and to make recommendations to the Agency regarding regulatory guidelines to govern pediatric cardiac catheterization programs and pediatric open-heart surgery programs in the state. The authorizing statute was amended in 2018 and again in 2019 with minor changes to membership appointment guidelines and added that the Agency for Health Care Administration's Secretary may request announced or unannounced site visits.

Currently, Florida Statute section 395.1055 requires the Agency to establish and administer the PCTAP, confirm appointments from the appropriate hospital Chief Executive Officers (CEOs), appoint at-large and alternate at-large members, conduct and document meetings, take recommendations from the panel, coordinate the development of work products from the panel, and develop administrative rule(s) that include minimum quality standards for the pediatric cardiac catheterization programs and pediatric cardiovascular surgery programs in the state. The Agency's Secretary may also appoint additional non-voting members from specific organizations listed in the statute; and may request site visits to be conducted by panel members.

<sup>&</sup>lt;sup>1</sup> Laws of Florida, 2017-151: http://laws.flrules.org/2017/151

<sup>&</sup>lt;sup>2</sup> Laws of Florida, 2018-24: http://laws.flrules.org/2018/24

<sup>&</sup>lt;sup>3</sup> Laws of Florida, 2019-138: <a href="http://laws.flrules.org/2019/138">http://laws.flrules.org/2019/138</a>

# Activities and Progress of the Panel

#### Rule Development

Proposed Rule 59A-3.248 was published in the Florida Administrative Register on March 10, 2021. The rule was challenged from multiple organizations, resulting in a Notice of Change published on May 25, 2021. The proposed rule was ultimately withdrawn on June 16, 2021. Further action on rule development and finalization are pending at this time.

## **Public Reporting**

#### Society of Thoracic Surgeons (STS) National Database

The Society of Thoracic Surgeons (STS), a national membership organization of surgeons, researchers, and allied health professionals, has developed a national registry and database where pediatric cardiac surgery programs across the nation submit clinical outcomes for specific procedures and conditions, including surgeries for congenital heart conditions. In return, the individual programs receive detailed statistical reports that include how the program compares to national benchmarks. The STS also hosts and maintains a public reporting website, including data specific to congenital heart surgeries, so that consumers can look up and compare outcomes across various programs. Participation in the STS congenital heart surgery registry is statutorily required of Florida-licensed pediatric cardiac surgery programs. The STS public website lists participating programs and displays mortality ratings based on the severity of procedures.

The most current published reports for Florida's pediatric cardiac surgery programs are included as Appendix A to this report. Additionally, the underlying STS congenital surgery data from Florida's licensed pediatric cardiac surgery programs will be obtained by the Agency, through a Data Sharing License Agreement (DSLA) with the STS as required in statute, for publication on the Agency's consumer-friendly health care transparency website, *FloridaHealthFinder.gov*.

#### **Future Panel Endeavors**

#### American College of Cardiology (IMPACT) Registry

The American College of Cardiology (ACC) hosts a number of patient data registries and produces statistical reports for participating cardiology programs, allowing individual programs to compare their quality and performance outcomes against national benchmarks. The ACC's *IMPACT* registry is specific to congenital heart disease. Communications with the ACC during 2018-2022 indicate that the organization has not yet developed a statewide reporting methodology. The ACC indicated that there will be significant changes to reporting and development of the registry in 2024. The Agency and PCTAP members will continue to explore options for which types of data would be most meaningful to consumers for public reporting of interventional cardiology outcomes.

#### Conclusion

Members of the PCTAP have been diligently working to implement changes to improve the care at all centers throughout the state, at the same time improving transparency of outcomes. The panel eagerly anticipate the initiation and completion of negotiated rule process regarding the proposed rule in the coming year. The Agency looks forward to the publishing of STS quality measures and data for each of Florida's licensed Pediatric Cardiac Surgery programs in the near future.

<sup>&</sup>lt;sup>4</sup> Florida Administrative Register: <a href="https://www.flrules.org/gateway/ruleNo.asp?id=59A-3.248">https://www.flrules.org/gateway/ruleNo.asp?id=59A-3.248</a>

# Appendix A

As a national leader in health care transparency and accountability, The Society of Thoracic Surgeons (STS) established the STS Public Reporting initiative, which allows participants in the STS National Database to voluntarily report their surgical outcomes to the public on the STS website. Public reporting is available for the following STS National Database components: The Adult Cardiac Surgery Database, General Thoracic Surgery Database, and Congenital Heart Surgery Database.

Available data reported from the Congenital Heart Surgery Database is shown below for each of Florida's licensed pediatric cardiac surgery programs.

**NOTE:** Results are based on a participant's unique group of patients (known as case mix) and the number of surgical procedures in each category. Results published are specific to the participant listed and are not intended for direct comparison to other participants.

For this Congenital Heart Surgery Database (CHSD) participant, rating is based on the overall observed-to-expected operative mortality ratio for all patients undergoing pediatric and/or congenital cardiac surgery.

Arnold Palmer Medical Center – Orlando, Florida									
Operative and Adjusted Operative Mortality (January 2019-December 2022)									
Population: Neonates, Infants, Children & Adults	# / Eligible	Observed	Expected	O/E Ratio (95% CI)	Adj. Rate (95% CI)				
Overall	16 / 443	3.61%	1.96%	1.84 (1.06, 2.96)	4.87 (2.8, 7.82)				
STAT Mortality Category 1	0 / 235	0%	0.72%	0 (0, 2.16)	0 (0, 1.39)				
STAT Mortality Category 2	3 / 107	2.8%	1.55%	1.81 (0.38, 5.16)	3.47 (0.72, 9.86)				
STAT Mortality Category 3	5 / 61	8.2%	3.23%	2.54 (0.84, 5.61)	8.88 (2.94, 19.62)				
STAT Mortality Category 4	4 / 26	15.38%	6.09%	2.53 (0.72, 5.73)	19.71 (5.58, 44.66)				
STAT Mortality Category 5	4 / 14	28.57%	12.7%	2.25 (0.66, 4.58)	33.15 (9.73, 67.41)				

Florida Hospital for Children – Orlando, Florida									
Operative and Adjusted Operative Mortality (January 2019-December 2022)									
Population: Neonates, Infants, Children & Adults	# / Eligible	Observed	Expected	O/E Ratio (95% CI)	Adj. Rate (95% CI)				
Overall	12 / 334	3.59%	2.21%	1.63 (0.85, 2.8)	4.29 (2.23, 7.4)				
STAT Mortality Category 1	1/190	0.53%	0.59%	0.89 (0.02, 4.92)	0.57 (0.01, 3.16)				
STAT Mortality Category 2	1/83	1.2%	2.31%	0.52 (0.01, 2.82)	0.99 (0.03, 5.39)				
STAT Mortality Category 3	3 / 30	10%	3.97%	2.52 (0.53, 6.68)	8.82 (1.86, 23.39)				
STAT Mortality Category 4	2 / 23	8.7%	8.32%	1.05 (0.13, 3.37)	8.15 (1, 26.29)				

STAT Mortality Category 5	5/8	62.5%	15.47%	4.04 (1.58, 5.91)	59.51 (23.31, 87.1)

Jackson Memorial Hospital – Miami, Florida										
Operative and Adjusted Operative Mortality (January 2019-December 2022)										
Population: Neonates, Infants, Children & Adults	# / Eligible	Observed	Expected	O/E Ratio (95% CI)	Adj. Rate (95% CI)					
Overall	9 / 184	4.89%	2.92%	1.68 (0.78, 3.11)	4.43 (2.05, 8.22)					
STAT Mortality Category 1	2 / 108	1.85%	0.81%	2.29 (0.28, 8.07)	1.47 (0.18, 5.18)					
STAT Mortality Category 2	1/36	2.78%	2.06%	1.35 (0.03, 7.07)	2.58 (0.07, 13.5)					
STAT Mortality Category 3	2/16	12.5%	3.19%	3.92 (0.49, 12.03)	13.73 (1.7, 42.12)					
STAT Mortality Category 4	2 / 16	12.5%	7.94%	1.58 (0.2, 4.83)	12.29 (1.53, 37.7)					

25%

2/8

24.64%

1.01 (0.13, 2.64)

14.94 (1.9, 38.91)

STAT Mortality Category 5

Joe DiMaggio Children's Hospital – Hollywood, Florida									
Operative and Adjusted Operative Mortality (January 2019-December 2022)									
Population: Neonates, Infants, Children & Adults	# / Eligible	Observed	Expected	O/E Ratio (95% CI)	Adj. Rate (95% CI)				
Overall	26 / 622	4.18%	2.44%	1.71 (1.13, 2.48)	4.52 (2.97, 6.56)				
STAT Mortality Category 1	3 / 330	0.91%	0.48%	1.9 (0.39, 5.51)	1.22 (0.25, 3.54)				
STAT Mortality Category 2	5 / 108	4.63%	1.9%	2.44 (0.8, 5.52)	4.66 (1.53, 10.54)				
STAT Mortality Category 3	3 / 84	3.57%	2.83%	1.26 (0.26, 3.57)	4.42 (0.92, 12.49)				
STAT Mortality Category 4	9 / 72	12.5%	8.25%	1.52 (0.71, 2.72)	11.83 (5.56, 21.2)				
STAT Mortality Category 5	6 / 28	21.43%	11.61%	1.84 (0.71, 3.53)	27.17 (10.52, 51.93)				

Johns Hopkins All Children's Hospital – St. Petersburg, Florida									
Operative and Adjusted Operative Mortality (January 2019-December 2022)									
Population: Neonates, Infants, Children & Adults	# / Eligible	Observed	Expected	O/E Ratio (95% CI)	Adj. Rate (95% CI)				
Overall	7 / 282	2.48%	2.67%	0.93 (0.38, 1.89)	2.46 (0.99, 5)				
STAT Mortality Category 1	2 / 141	1.42%	0.84%	1.69 (0.21, 6)	1.09 (0.13, 3.85)				
STAT Mortality Category 2	2 / 69	2.9%	1.96%	1.48 (0.18, 5.15)	2.83 (0.34, 9.84)				
STAT Mortality Category 3	2 / 42	4.76%	4.26%	1.12 (0.14, 3.79)	3.91 (0.48, 13.27)				

STAT Mortality Category 4	0 / 14	0%	9.17%	0 (0, 2.52)	0 (0, 19.7)
STAT Mortality Category 5	1/16	6.25%	11.95%	0.52 (0.01, 2.53)	7.71 (0.19, 37.27)

Nemours Children's Hospital – Orlando, Florida									
Operative and Adjusted Operative Mortality (January 2019-December 2022)									
Population: Neonates, Infants, Children & Adults	# / Eligible	Observed	Expected	O/E Ratio (95% CI)	Adj. Rate (95% CI)				
Overall	3 / 307	0.98%	1.61%	0.61 (0.13, 1.76)	1.6 (0.33, 4.65)				
STAT Mortality Category 1	0 / 203	0%	0.46%	0 (0, 3.95)	0 (0, 2.54)				
STAT Mortality Category 2	1/49	2.04%	1.8%	1.13 (0.03, 6.02)	2.16 (0.05, 11.51)				
STAT Mortality Category 3	0 / 25	0%	2.64%	0 (0, 5.19)	0 (0, 18.16)				
STAT Mortality Category 4	1/22	4.55%	7.32%	0.62 (0.02, 3.12)	4.84 (0.12, 24.33)				
STAT Mortality Category 5	1/8	12.5%	10.71%	1.17 (0.03, 4.92)	17.2 (0.43, 72.44)				

Nicklaus Children's Hospital – Miami, Florida									
Operative and Adjusted Operative Mortality (January 2019-December 2022)									
Population: Neonates, Infants, Children & Adults	# / Eligible	Observed	Expected	O/E Ratio (95% CI)	Adj. Rate (95% CI)				
Overall	20 / 730	2.74%	3.11%	0.88 (0.54, 1.35)	2.32 (1.43, 3.56)				
STAT Mortality Category 1	0 / 401	0%	0.64%	0 (0, 1.43)	0 (0, 0.92)				
STAT Mortality Category 2	4 / 150	2.67%	2.49%	1.07 (0.29, 2.68)	2.04 (0.56, 5.12)				
STAT Mortality Category 3	1/50	2%	3.85%	0.52 (0.01, 2.76)	1.82 (0.05, 9.67)				
STAT Mortality Category 4	6 / 78	7.69%	7.31%	1.05 (0.39, 2.19)	8.21 (3.07, 17.07)				
STAT Mortality Category 5	9/51	17.65%	17.22%	1.02 (0.49, 1.79)	15.09 (7.18, 26.4)				

St. Joseph's Children's Hospital BayCare Health System – Tampa, Florida									
Operative and Adjusted Operative Mortality (January 2019-December 2022)									
Population: Neonates, Infants, Children & Adults	# / Eligible	Observed	Expected	O/E Ratio (95% CI)	Adj. Rate (95% CI)				
Overall	11 / 645	1.71%	2.23%	0.76 (0.38, 1.36)	2.02 (1.01, 3.58)				
STAT Mortality Category 1	0/351	0%	0.52%	0 (0, 2)	0 (0, 1.28)				
STAT Mortality Category 2	2 / 142	1.41%	1.69%	0.84 (0.1, 2.96)	1.6 (0.19, 5.66)				

STAT Mortality Category 3	0 / 80	0%	3.39%	0 (0, 1.33)	0 (0, 4.65)
STAT Mortality Category 4	2 / 45	4.44%	8.86%	0.5 (0.06, 1.71)	3.91 (0.48, 13.34)
STAT Mortality Category 5	7 / 27	25.93%	12.86%	2.02 (0.86, 3.6)	29.7 (12.73, 53.03)

UF Health Shands Children's Hospital — Gainesville, Florida  Operative and Adjusted Operative Mortality (January 2019-December 2022)								
Overall	17 / 871	1.95%	2.55%	0.77 (0.45, 1.22)	2.02 (1.18, 3.22)			
STAT Mortality Category 1	2 / 414	0.48%	0.52%	0.94 (0.11, 3.36)	0.6 (0.07, 2.16)			
STAT Mortality Category 2	1 / 164	0.61%	1.71%	0.36 (0.01, 1.96)	0.68 (0.02, 3.74)			
STAT Mortality Category 3	6 / 167	3.59%	3.5%	1.03 (0.38, 2.19)	3.6 (1.33, 7.66)			
STAT Mortality Category 4	7 / 70	10%	8.12%	1.23 (0.51, 2.41)	9.61 (3.96, 18.76)			

1.79%

10.18%

0.18 (0, 0.94)

2.58 (0.07, 13.81)

1/56

Wolfson Children's Hospital – Jacksonville, Florida  Operative and Adjusted Operative Mortality (January 2019-December 2022)						
Overall	8 / 481	1.66%	1.59%	1.05 (0.45, 2.04)	2.76 (1.2, 5.39)	
TAT Mortality Category 1	1/288	0.35%	0.5%	0.69 (0.02, 3.83)	0.44 (0.01, 2.46)	
STAT Mortality Category 2	2 / 104	1.92%	1.69%	1.14 (0.14, 4.02)	2.18 (0.26, 7.67)	
STAT Mortality Category 3	1/57	1.75%	2.56%	0.69 (0.02, 3.67)	2.4 (0.06, 12.84)	
STAT Mortality Category 4	2 / 25	8%	7.68%	1.04 (0.13, 3.39)	8.13 (1, 26.45)	
TAT Mortality Category 5	2/7	28.57%	15.42%	1.85 (0.24, 4.6)	27.29 (3.51, 67.78)	

#### \*This information can be found at: Congenital Heart Surgery Public Reporting | STS Public Reporting

STAT Mortality Category 5

Arnold Palmer Medical Center	Orlando, Florida
Florida Hospital for Children	Orlando, Florida
Jackson Memorial Hospital	Miami, Florida
Joe DiMaggio Children's Hospital	Hollywood, Florida
Johns Hopkins All Children's Hospital	St. Petersburg, Florida
Nemours Children's Hospital	Orlando, Florida

Nicklaus Children's Hospital	Miami, Florida
St. Joseph's Children's Hospital BayCare Health System	Tampa, Florida
UF Health Shands Children's Hospital	Gainesville, Florida
Wolfson Children's Hospital	Jacksonville, Florida