Pediatric Congenital Cardiac Surgery

in New York State

2006 – 2009

New York State Department of Health
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MESSAGE FROM THE DEPARTMENT OF HEALTH

We are very pleased to provide the information in this booklet for health care providers and for the families of children who need heart surgery. This report summarizes outcomes for pediatric patients undergoing surgery to correct congenital heart defects. Hospital-specific mortality rates that have been adjusted to account for differences in patient severity of illness are included along with the risk factors associated with in-hospital mortality for these procedures. These analyses represent one component of our ongoing efforts to provide comprehensive monitoring and assessment information for both patients and providers. This is the third report of risk-adjusted outcomes for pediatric cardiac surgery in New York State (NYS). New York is the only state in the country that we are aware of to evaluate and release this kind of information for pediatric cardiac surgery.

The term congenital heart defect represents a broad range of abnormalities that may be present at birth. According to the National Heart Lung and Blood Institute, about 1 in every 125 newborns is affected by a congenital heart defect. More than 35 different types of congenital heart defects have been identified. Until recent years, the most serious defects were thought to be untreatable. However, as scientific knowledge and technology have increased, more cases have been identified and the range of surgical options to correct them or alleviate their damaging effects has grown.

Evaluating pediatric cardiac surgery data represents special challenges because of the wide range of diagnoses and procedures involved. However, with the guidance of the New York State Cardiac Advisory Committee (CAC), we have been able to develop a statistical model that allows us to monitor and compare outcomes across hospitals. Similar analyses in adult cardiac surgery have been helpful both in documenting the excellent care provided in NYS centers and in continuing to improve care. We believe that similar improvements will be achieved by sharing these data for pediatric cardiac surgery.

If your child has been diagnosed with a heart defect, it is very important that a specialist in pediatric cardiology evaluate him or her. If surgery is being considered, the pediatric cardiologist and cardiac surgeon will be able to explain the special features of your child's condition and discuss the various treatment options.

We extend our appreciation to the providers of this state and the CAC for their efforts in developing and refining this remarkable cooperative quality improvement initiative. The New York State Department of Health (DOH) will continue to work in partnership with hospitals and physicians to ensure the continued high quality of pediatric congenital heart surgery available in NYS.

INTRODUCTION

This booklet is intended for health care providers and families of children who have a congenital heart defect. It provides information on risk factors associated with pediatric congenital heart surgery and lists hospital specific mortality rates that have been risk-adjusted to account for differences in patient severity of illness. New York State has taken a leadership role in setting standards for cardiac services, monitoring outcomes, and sharing performance data with patients, hospitals, and physicians. Hospitals and doctors involved in the care of pediatric cardiac patients have worked in cooperation with the DOH and the CAC to compile accurate and meaningful data for use in enhancing quality of care. The data in this report are based on the New York State Pediatric Cardiac Surgery Reporting System. This system is used to gather information on each patient's diagnoses, the actual procedure performed and other clinical factors that may impact outcomes. As part of the reporting system, hospitals have the ability to track their own data and compare their experience to statewide outcomes. We believe that this process has been instrumental in achieving the excellent outcomes that are experienced in centers across NYS.

Congenital Heart Defects

Congenital heart defects are a leading cause of death in infancy. Congenital heart defects may take many forms and represent a wide range of risk. Some simple defects, such as a small opening between heart chambers, may be consistent with good health and a normal life span. Other defects, such as an under developed heart chamber or valve may result in shock in the first hours or days of life unless rapid and effective action is taken. Findings of an unusual heart murmur, cyanosis (blueness), or fast breathing indicate the need for consultation by a pediatric cardiologist (child heart specialist). In some cases, only a physical examination by a pediatric cardiologist is required. If a significant heart problem is suspected, an echocardiogram (ultrasound of the heart) is obtained. If further information is required, a heart catheterization is performed in which a small catheter or tube is inserted into a blood vessel and threaded into heart chambers and large blood vessels to measure oxygen levels. A special dye may be injected through the catheter making it possible to take internal pictures of certain parts of the heart or major vessels. For some heart defects, special devices may be inserted into the heart through a catheter to open narrowed valves or vessels, or to close simple holes within the heart.

If the patient requires surgery to correct the defect, a decision regarding the timing and type of surgery is made jointly between the cardiovascular surgeon and the pediatric cardiologist. During and after surgery, the cardiovascular surgeon leads a team consisting of anesthesiologists, perfusionists, post-operative care specialists, nurses and other relevant care providers to coordinate the needs of the patient and family. Following discharge, the patient is followed jointly by the surgeon, pediatric cardiologist, and primary care provider. Some complex heart defects require a series of operations to allow for growth or to compensate for a significant malformation. Careful joint planning by the entire team of providers is needed for these patients.

Some simple heart defects can be considered "cured" by surgery. For other patients, good health is restored, but lifelong monitoring to prevent or treat secondary problems is required. Because of the extreme variability of congenital heart defects, the timing and type of surgery can vary from patient to patient. The surgical plan may also vary from one surgical center to another when there is no clear advantage of a single approach. When experience has shown one surgical approach superior to another, it is adopted by all centers. Some patients who are at very high risk for surgery are referred to a specific center where a special technique, that is not performed elsewhere, can be performed. For this reason, it is not possible to determine the level of expertise of a program by looking at the simple mortality rate. It is necessary to compare one center's experience with the results of others performing operations of equal complexity.

In examining the results of a single surgical center, it is important to remember that many factors other than the techniques of surgery are responsible for the final outcome. To fairly compare the outcomes of different surgical programs, it is necessary to recognize the extensive patient variability. Patient demographics, diagnoses, recommended procedures and health conditions all must be taken into account. When heart surgery is recommended for your child, it is important to speak with your pediatric cardiologist and cardiac surgeon. They will be able to explain the special features of your child's defect and the surgical experience of a particular center. A listing of the wide range of pediatric congenital heart disease diagnoses associated with pediatric cardiac surgery is provided in Appendix 1.

HEALTH DEPARTMENT PROGRAM

The New York State Department of Health has been studying the effects of patient and treatment characteristics on outcomes for patients undergoing heart surgery for many years. Detailed statistical analyses of the information received from the study have been conducted under the guidance of the CAC, a group of independent practicing cardiac surgeons, cardiologists, and other professionals in related fields.

The results have been used to create a cardiac profile system that assesses the performance of hospitals, taking into account the severity of individual patient's pre-operative conditions. Coronary artery bypass surgery results have been assessed since 1989; percutaneous coronary intervention results were released in 1996 for the first time. The first Pediatric Congenital Cardiac Surgery Report, based on 1997-1999 data, was released in 2004. This report, based on 2006-2009 data is the third report. This report differs from the most recent report in that the methodology has been altered slightly to best capture how the important factors of age and type of heart defect contribute to the risk of in-hospital mortality for pediatric patients undergoing cardiac surgery. This methodology is further described under "Assessing Patient Risk".

Designed to improve health in pediatric patients with congenital heart disease, the analyses in this report are aimed at:

- Understanding the health risks of patients that adversely affect how they will fare during and after pediatric congenital cardiac surgery;
- Assessing and evaluating the results of the surgical treatments for congenital heart disease;
- Improving cardiac care for pediatric patients; and
- Providing information to help patients' families make better decisions about the care of their children.

We encourage doctors to discuss the information in this report with their patients' families and colleagues as they develop treatment plans. While these statistics are an important tool in making informed health care choices, individual treatment plans must be made by doctors and families together after careful consideration of all pertinent factors. It is important to recognize that many things can influence the outcome of congenital heart surgery. These include the patient's health before the procedure, the skill of the operating team, and general aftercare. In addition, keep in mind that the information in this booklet does not include data after 2009. Important changes may have taken place in some hospitals since that time.

PATIENT POPULATION

Pediatric patients (age <18 years) undergoing congenital cardiac surgery in New York State hospitals who were discharged between January 1, 2006, and December 31, 2009, are included in these analyses. Patients with any non-congenital cardiac disease and those who received a heart or lung transplant or an artificial heart during an admission were excluded from the analysis. Observed, expected, and risk-adjusted mortality rates are reported for patients undergoing congenital cardiac surgery in each of the 12 New York State hospitals approved to perform cardiac surgery on pediatric patients between 2006 and 2009.

RISK-ADJUSTMENT FOR ASSESSING PROVIDER PERFORMANCE

Hospital performance is an important factor that directly relates to patient ourcomes. Whether patients recover quickly, experience complications or die following a procedure is in part a result of the kind of medical care they receive. It is difficult, however, to compare outcomes among hospitals that treat different types of patients. Hospitals with sicker patients may have higher rates of complications and death than other hospitals in the State. The following describes how the DOH adjusts for patient risk in assessing outcomes of care in different hospitals.

Data Collection, Data Validation and Identifying In-Hospital Deaths

As part of the risk-adjustment process, hospitals in NYS where pediatric cardiac surgery is performed provide information to the DOH for each patient undergoing those procedures. Each hospital's cardiac surgery department collects data concerning patients' demographic and clinical characteristics including age, sex, pediatric congenital diagnosis and comorbidities. Approximately 25 of these characteristics (or risk factors) are collected for each patient. These data, along with information about the hospital, physician, procedure performed and the patient's status at discharge, are entered into a computer and sent to the DOH for analysis. Data are verified through the review of unusual reporting frequencies, cross-matching of pediatric cardiac surgery data with other DOH databases and a review of medical records for a selected sample of cases. These activities are extremely helpful in ensuring consistent interpretation of data elements across hospitals.

The analysis is based on deaths occurring during the same hospital stay in which the patient underwent pediatric congenital cardiac surgery. In this report, an in-hospital death is defined as a patient who died subsequent to cardiac surgery during the same acute care admission or was discharged to hospice.

Assessing Patient Risk

Each person who has a congenital heart defect has a unique history. A cardiac profile system has been developed to evaluate the risk of treatment for each individual patient based on his or her history, weighing the important health factors for that person based on the experiences of patients who have had similar health histories in recent years. All of the important risk factors for each patient are combined to create his or her risk profile.

The method used to assess risk in this report differs somewhat from the method used in the previous report. In that report, patients were initially placed into 14 groups on the basis of important determinants of mortality: age, whether the heart is univentircular or biventricular and the severity of the congenital diagnosis at admission (high, medium, low). A univentricular heart, or "single ventricle", is a heart that has only one ventricle capable of sustaining a full cardiac output. In addition to these 14 groups, patients were categorized according to whether or not they had other conditions (comorbidities) that were shown to be predictors of mortality.

In this report, each of the important determinants of mortality (age, univentricular/ biventricular anatomy and severity of diagnosis) serve as independent predictors of mortality in the risk-adjustment calculation. In addition, patients under 1 year of age are categorized according to whether or not they weighed less than 2000 grams (just under four and a half pounds) at birth, another factor that has been shown to be significantly related to in-hospital mortality. Statistical analyses show that splitting out the various patient characteristics in this new way is preferable because it allows for more precise prediction for each individual patient and it does not suffer from estimation problems related to small sample sizes for some groups of patients

However, clustering cases into similar groups to look at outcomes for various types of patients is useful to providers in assessing their own performance and in helping to understand the risk associated with particular cases. For this purpose, Appendix 2 presents mortality rates for groups of patients according to age, number of ventricles and risk. Appendix 3 describes the statistical model used to develop the risk-adjusted mortality rates shown in Table 1.

Predicting Patient Mortality Rates for Hospitals

The statistical methods used to predict mortality on the basis of the significant risk factors and diagnoses are tested to determine whether they are sufficiently accurate in predicting mortality for patients who are extremely ill prior to admission as well as for patients who are relatively healthy. These tests have confirmed that the models are reasonably accurate in predicting how patients at all different risk levels will fare when undergoing pediatric congenital cardiac surgery.

The resulting rate is the predicted or expected mortality rate (EMR) and is an estimate of what the hospital's mortality rate would have been if the hospital's performance was identical to the State performance. EMR is therefore an indicator of patient severity of illness. A hospital's EMR is contrasted with its observed mortality rate (OMR), which is the

number of pediatric congenital cardiac surgery patients who died in that hospital divided by the total number of pediatric congenital cardiac surgery patients in that hospital.

Computing the Risk-Adjusted Mortality Rate

The risk-adjusted mortality rate (RAMR) represents the best estimate, based on the associated statistical model, of what the hospital's mortality rate would have been if the hospital had a mix of patients identical to the statewide mix. Thus, the RAMR has, to the extent possible, ironed out differences among hospitals in patient severity of illness, since it arrives at a mortality rate for each hospital based on an identical group of patients.

To calculate the RAMR, the OMR is divided by the hospital's EMR. If the resulting ratio is larger than one, the hospital has a higher mortality rate than expected on the basis of the patient mix; if it is smaller than one, the hospital has a lower mortality rate than expected from its patient mix. The ratio is then multiplied by the overall statewide mortality rate (3.35 percent for 2006-2009) to obtain the hospital's risk-adjusted rate.

There is no Statewide EMR or RAMR, because the statewide data is not risk-adjusted. The Statewide OMR (number of total cases divided by number of total deaths) serves as the basis for comparison for each hospital's EMR and RAMR.

Interpreting the Risk-Adjusted Mortality Rate

If the RAMR is significantly lower than the statewide mortality rate, the hospital has a better performance than the state as a whole; if the RAMR is significantly higher than the statewide mortality rate, the hospital's performance is worse than the state as a whole. Significant differences, higher and lower, are identified in Table 1 with one or two asterisks, respectively.

The RAMR is used in this report as a measure of the quality of care provided by hospitals. There are reasons that a provider's risk-adjusted rate may not be indicative of its true quality. However, we have developed mechanisms for limiting the impact of these issues.

For example, extreme outcome rates may occur due to chance alone. This is particularly true for low-volume providers, for whom very high or very low rates are more likely to occur than for high-volume providers. Expected ranges or confidence intervals are included as part of the reported results in an attempt to prevent misinterpretation of differences caused by chance variation.

Differences in hospital coding of risk factors could be an additional reason that a hospital's risk-adjusted mortality rate may not be reflective of their quality of care. The DOH monitors the quality of coded data by reviewing patients' medical records to confirm the presence of key risk factors.

Some commentators have suggested that patient severity of illness may not be accurately estimated because some risk factors are not included in the data system, and this could lead to misleading risk-adjusted rates. This is not likely because the NYS data system has been reviewed by practicing physicians in the field and is updated continually

How This Initiative Contributes to Quality Improvement

The goal of the DOH and the CAC is to improve the quality of care related to cardiac surgery in NYS. Providing the hospitals and cardiac surgeons in NYS with data about their own outcomes for these procedures allows them to examine the quality of the care they provide and to identify areas that need improvement.

The data collected and analyzed in this program are reviewed by the CAC. Committee members assist with interpretation and advise the DOH regarding hospitals and surgeons that may need special attention. Committee members have also conducted site visits to particular hospitals and have recommended that some hospitals obtain the expertise of outside consultants to design improvements for their programs.

The overall results of this program of ongoing review show that significant progress is being made. In response to the program's results for surgery, facilities have refined patient criteria, evaluated patients more closely for pre–operative risks and directed them to the appropriate surgeon. More importantly, many hospitals have identified medical care process problems that have led to less than optimal outcomes, and have altered those processes to achieve improved results.

2006-2009 HOSPITAL OUTCOMES FOR PEDIATRIC CONGENITAL CARDIAC SURGERY

Table 1 presents the 2006-2009 Pediatric Cardiac Surgery results for the 12 hospitals performing congenital heart surgery in pediatric patients in NYS. The table contains, for each hospital, the number of pediatric congenital cardiac procedures performed resulting in discharges between 2006-2009, the number of in-hospital deaths, the OMR, the EMR based on the statistical model presented in Appendix 3, the RAMR, and the 95% confidence interval for the RAMR.

As indicated in Table 1, the overall mortality for the 5,162 pediatric congenital cardiac surgeries performed at 12 NYS hospitals and discharged between January 1, 2006, and December 31, 2009, was 3.35 percent. This mortality rate is substantially lower than that reported in the most recent report, which was 4.08 percent for patients discharged between January 1, 2002, and December 31, 2005. Hospital observed mortality for all pediatric congenital cardiac surgery patients ranged from 0.00 to 5.29 percent. The range in expected mortality, which measures patient severity of illness, was 0.82 percent to 4.56 percent.

The RAMRs, which are used to measure performance, ranged from 0.00 to 6.91 percent. Two hospitals (Long Island Jewish Medical Center in New Hyde Park and Strong Memorial Hospital in Rochester) had RAMRs that were significantly higher than the statewide rate. One hospital (Columbia Presbyterian Medical Center in Manhattan) had a RAMR that was significantly lower than the statewide rate.

Note on Hospitals Not Performing Pediatric Cardiac Surgery During Entire 2006-2009 Period

Two hospitals did not perform pediatric congenital cardiac surgery for the entire four-year time period on which this report is based. Children's Hospital in Buffalo did not perform any pediatric cardiac surgery after July 2006. The last pediatric cardiac surgery at University Hospital at Stony Brook was performed in August 2008.

Definitions of key terms are as follows:

The observed mortality rate (OMR) is the observed number of deaths divided by the total number of pediatric patients who underwent congenital heart surgery.

The expected mortality rate (EMR) is the sum of the predicted probabilities of death for all patients divided by the total number of patients.

The risk-adjusted mortality rate (RAMR) is the best estimate, based on the statistical model, of what the provider's mortality rate would have been if the provider had a mix of patients identical to the statewide mix. The RAMR is obtained by first dividing the OMR by the EMR, and then multiplying the quotient by the statewide mortality rate (3.35 for all pediatric congenital cardiac surgery patients in 2006-2009).

Confidence intervals are used to identify which hospitals had more or fewer deaths than expected given the risk factors of their patients. The confidence interval identifies the range in which the calculated RAMR may fall. Hospitals with significantly higher rates than expected after adjusting for risk are those where the confidence interval range falls entirely above the statewide mortality rate. Hospitals with significantly lower RAMRs than expected given the severity of illness of their patients before pediatric congenital cardiac surgery have the confidence interval range entirely below the statewide rate.

Table 1. Hospital Observed, Expected, and Risk-Adjusted Mortality Rates for Pediatric Congenital Cardiac Surgery in New York State, 2006-2009 Discharges (Listed Alphabetically by Hospital)

Hospital	Cases	Deaths	OMR	EMR	RAMR	95% CI for RAMR
Albany Medical Center	309	7	2.27	3.23	2.35	(0.94, 4.85)
Childrens - Buffalo	19	0	0.00	0.82	0.00	(0.00,78.80)
Columbia Presbyterian-NYP	1624	43	2.65	4.56	1.95 **	(1.41, 2.62)
LIJ Medical Center	603	26	4.31	2.56	5.65 *	(3.69, 8.28)
Montefiore - Moses	265	10	3.77	1.83	6.91	(3.31,12.71)
Mount Sinai	584	19	3.25	2.96	3.68	(2.22, 5.75)
NYU Hospitals Center	292	8	2.74	1.85	4.97	(2.14, 9.79)
Strong Memorial	719	38	5.29	3.35	5.29 *	(3.74, 7.26)
Univ. Hosp. - Stony Brook	43	0	0.00	1.15	0.00	(0.00,24.95)
Univ. Hosp. - Upstate	135	3	2.22	1.52	4.91	(0.99,14.35)
Weill Cornell-NYP	310	12	3.87	2.82	4.60	(2.38, 8.04)
Westchester Medical Center	259	7	2.70	4.06	2.23	(0.89, 4.60)
Total	**5162**	**173**	**3.35**			

* Risk Adjusted Mortality Rate significantly higher than statewide rate based on 95 percent confidence interval.
** Risk Adjusted Mortality Rate significantly lower than statewide rate based on 95 percent confidence interval.

APPENDIX 1
Pediatric Congenital Cardiac Diagnoses in New York State, 2006-2009

The following table is a complete list of all congenital diagnoses that were reported for pediatric congenital cardiac surgery patients between 2006-2009. To help gain a better understanding of the variety of diagnoses present in the pediatric population of New York State, the table lists the total number of cases performed, the total number of deaths, observed mortality rate and the percent of all patients operated on between 2006-2009 that had each diagnosis. The table presents this information first for patients who had the diagnosis as their only diagnosis, and then for patients who had the diagnosis in conjunction with other diagnoses.

	Sole Diagnosis				Any Diagnosis			
Code Diagnosis	Cases	Deaths	OMR	Prevalence	Cases	Deaths	OMR	Prevalence
10 Atrial Situs: Situs Inversus	.	.	.	.	22	1	4.55	0.43
11 Atrial Situs: Situs Ambiguous/Heterotaxy Syndrome	.	.	.	.	73	6	8.22	1.41
20 Cardiac Position: Dextrocardia	.	.	.	.	61	1	1.64	1.18
21 Cardiac Position: Mesocardia	.	.	.	.	7	0	0.00	0.14
22 Cardiac Position: Ectopia cordis	.	.	.	.	7	0	0.00	0.14
100 Pulmonary Veins: Partial Anomalous Return	12	0	0.00	0.23	131	4	3.05	2.54
101 Pulmonary Veins: Total Anomalous Return: Supracardiac	23	0	0.00	0.45	63	8	12.70	1.22
102 Pulmonary Veins: Total Anomalous Return: Cardiac	6	0	0.00	0.12	26	2	7.69	0.50
103 Pulmonary Veins: Total Anomalous Return: Infracardiac	10	0	0.00	0.19	31	3	9.68	0.60
104 Pulmonary Veins: Total Anomalous Return: Mixed	1	0	0.00	0.02	15	0	0.00	0.29
105 Pulmonary Veins: Pulmonary Vein Stenosis	8	0	0.00	0.15	27	6	22.22	0.52
106 Pulmonary Veins: Cor Triatrialum	4	0	0.00	0.08	20	2	10.00	0.39
110 Atrial Septum: Secundum ASD	256	0	0.00	4.96	803	19	2.37	15.56
111 Atrial Septum: Single Atrium	2	0	0.00	0.04	13	1	7.69	0.25
112 Atrial Septum: Unroofed Coronary Sinus	1	0	0.00	0.02	7	0	0.00	0.14
113 Atrial Septum: Sinus Venosus ASD	24	0	0.00	0.46	142	1	0.70	2.75
114 Atrial Septum: PFO	2	0	0.00	0.04	326	8	2.45	6.32
120 Tricuspid: Ebsteins Anomaly	15	1	6.67	0.29	46	5	10.87	0.89
121 Tricuspid: Tricuspid Stenosis	1	0	0.00	0.02	16	2	12.50	0.31
122 Tricuspid: Tricuspid Regurgitation	2	0	0.00	0.04	107	2	1.87	2.07
123 Tricuspid: Straddling Tricuspid Valve	.	.	.	.	5	0	0.00	0.10
130 Mitral: Supravalvular Mitral Stenosis	3	0	0.00	0.06	12	0	0.00	0.23
131 Mitral: Valvular Mitral Stenosis	10	0	0.00	0.19	45	4	8.89	0.87
132 Mitral: Subvalvular Mitral Stenosis	3	0	0.00	0.06	8	0	0.00	0.15
133 Mitral: Mitral Regurgitation	34	2	5.88	0.66	139	6	4.32	2.69
134 Mitral: Straddling Mitral Valve	.	.	.	.	3	0	0.00	0.06
135 Mitral: Papillary Muscle Abnormality	.	.	.	.	4	0	0.00	0.08
140 Common AV Valve: Stenosis	.	.	.	.	5	0	0.00	0.10
141 Common AV Valve: Regurgitation	.	.	.	.	13	0	0.00	0.25
142 Common AV Valve: Malaligned	.	.	.	.	2	0	0.00	0.04
150 Ventricular Septum: Perimembranous VSD	219	3	1.37	4.24	805	20	2.48	15.59
151 Ventricular Septum: Doubly committed VSD	24	0	0.00	0.46	75	0	0.00	1.45
152 Ventricular Septum: Inlet VSD	14	0	0.00	0.27	72	3	4.17	1.39
153 Ventricular Septum: Muscular VSD	10	0	0.00	0.19	76	2	2.63	1.47
154 Ventricular Septum: Multiple VSDs	8	0	0.00	0.15	43	2	4.65	0.83

Appendix 1 (continued) Pediatric Congenital Cardiac Diagnoses in New York State 2006 - 2009.

Code	Diagnosis	Sole Diagnosis Cases	Deaths	OMR	Prevalence	Any Diagnosis Cases	Deaths	OMR	Prevalence
160	AVSD: Partial AVSD (Primum ASD)	57	0	0.00	1.10	115	3	2.61	2.23
161	AVSD: Complete AVSD: Balanced	98	0	0.00	1.90	263	8	3.04	5.09
162	AVSD: Complete AVSD: Unbalanced	18	1	5.56	0.35	123	14	11.38	2.38
170	Single Ventricle: Double/Common Inlet LV	25	0	0.00	0.48	75	2	2.67	1.45
171	Single Ventricle: Double/Common Inlet RV	4	0	0.00	0.08	17	0	0.00	0.33
172	Single Ventricle: Tricuspid Atresia: With IVS	24	0	0.00	0.46	48	3	6.25	0.93
173	Single Ventricle: Tricuspid Atresia: With VSD	65	0	0.00	1.26	114	2	1.75	2.21
174	Single Ventricle: Tricuspid Atresia: With TGA	8	0	0.00	0.15	24	1	4.17	0.46
175	Single Ventricle: Mitral Atresia	5	0	0.00	0.10	37	5	13.51	0.72
176	Single Ventricle: Indeterminate Ventricle	2	0	0.00	0.04	12	1	8.33	0.23
180	Single Ventricle: Hypoplastic RV: Pulmonary atresia with IVS	29	2	6.90	0.56	74	6	8.11	1.43
181	Single Ventricle: Hypoplastic RV: Other type of hypoplastic RV	9	0	0.00	0.17	43	5	11.63	0.83
190	Single Ventricle: Hypoplastic LV: Classical HLHS	227	18	7.93	4.40	295	25	8.47	5.71
191	Single Ventricle: Hypoplastic LV: Any other Hypoplastic LV	45	4	8.89	0.87	151	14	9.27	2.93
200	Outflow: Pulmonary	3	0	0.00	0.06	10	2	20.00	0.19
201	Outflow: Pulmonary: Pulmonary Valve Stenosis	41	0	0.00	0.79	283	11	3.89	5.48
202	Outflow: Pulmonary: Subvalvular/ Infundibular Pulmonary Stenosis	13	0	0.00	0.25	158	5	3.16	3.06
203	Outflow: Pulmonary: Double Chamber Right Ventricle	7	0	0.00	0.14	59	1	1.69	1.14
204	Outflow: Pulmonary: Branch Pulmonary Artery Stenosis	9	0	0.00	0.17	216	8	3.70	4.18
205	Outflow: Pulmonary: Hypoplastic Pulmonary Arteries	.	.	.	.	37	2	5.41	0.72
206	Outflow: Pulmonary: Pulmonary Valve Regurgitation	16	0	0.00	0.31	86	1	1.16	1.67
207	Outflow: Pulmonary: Main Pulmonary Artery Atresia	6	1	16.67	0.12	106	21	19.81	2.05
208	Outflow: Pulmonary: Branch Pulmonary Artery Atresia	1	0	0.00	0.02	24	2	8.33	0.46
210	Outflow: Aortic: Valvular Aortic Stenosis	12	1	8.33	0.23	81	11	13.58	1.57
211	Outflow: Aortic: Subvalvular Aortic Stenosis: Discrete	80	0	0.00	1.55	148	5	3.38	2.87
212	Outflow: Aortic: Subvalvular Aortic Stenosis: Long Segment/Tunnel	14	0	0.00	0.27	51	2	3.92	0.99
220	Outflow: Aortic: Supravalvular Aortic Stenosis	12	0	0.00	0.23	39	3	7.69	0.76
230	Outflow: Aortic: Aortic Valve Atresia	2	0	0.00	0.04	9	0	0.00	0.17
231	Outflow: Aortic: Aortic Valve Regurgitation	30	0	0.00	0.58	113	0	0.00	2.19
232	Outflow: Aortic: Aorto-Ventricular Tunnel	1	0	0.00	0.02	2	0	0.00	0.04
240	TOF: RV-PA Continuity	227	1	0.44	4.40	448	7	1.56	8.68
241	TOF: TOF with Pulmonary Valve Atresia	84	4	4.76	1.63	219	12	5.48	4.24
242	TOF: Absent Pulmonary Valve Syndrome	20	1	5.00	0.39	31	2	6.45	0.60
250	Truncus Arterious: Type I	17	1	5.88	0.33	49	2	4.08	0.95
251	Truncus Arterious: Type II	9	2	22.22	0.17	21	2	9.52	0.41
252	Truncus Arterious: Type III	.	.	.	.	3	0	0.00	0.06
260	TGA: D-TGA	58	3	5.17	1.12	350	19	5.43	6.78
261	TGA: Congenitally Corrected Transposition	3	0	0.00	0.06	58	0	0.00	1.12
270	Double Outlet RV: Subaortic VSD	14	0	0.00	0.27	107	4	3.74	2.07
271	Double Outlet RV: Subpulmonic VSD	8	0	0.00	0.15	50	7	14.00	0.97
272	Double Outlet RV: Uncommitted VSD	4	0	0.00	0.08	32	3	9.38	0.62
273	Double Outlet RV: Doubly Committed VSD	6	0	0.00	0.12	26	1	3.85	0.50
274	Double Outlet RV: Restrictive VSD	.	.	.	.	3	0	0.00	0.06

Appendix 1 (continued) Pediatric Congenital Cardiac Diagnoses in New York State 2006 - 2009.

Code Diagnosis	Sole Diagnosis				Any Diagnosis			
	Cases	Deaths	OMR	Prevalence	Cases	Deaths	OMR	Prevalence
280 Great Vessel: Aortopulmonary Window	8	0	0.00	0.15	19	0	0.00	0.37
281 Great Vessel: Patent Ductus Arteriosus	141	5	3.55	2.73	929	33	3.55	18.00
282 Great Vessel: Origin of L/R PA from Aorta	4	0	0.00	0.08	7	0	0.00	0.14
283 Great Vessel: Sinus of Valsalva Aneurysm/Fistula	1	0	0.00	0.02	5	1	20.00	0.10
284 Great Vessel: Aortic Coarctation	190	0	0.00	3.68	492	18	3.66	9.53
285 Great Vessel: Aortic Interruption	6	0	0.00	0.12	119	8	6.72	2.31
286 Great Vessel: Aortic Aneurysm: Ascending	4	0	0.00	0.08	8	0	0.00	0.15
287 Great Vessel: Aortic Aneurysm: Descending	1	0	0.00	0.02	4	0	0.00	0.08
288 Great Vessel: Aortic Aneurysm: Transverse	.	.	.	.	2	1	50.00	0.04
289 Great Vessel: Vascular Ring	58	0	0.00	1.12	82	0	0.00	1.59
290 Great Vessel: Origin of LPA from RPA (PA sling)	3	0	0.00	0.06	9	0	0.00	0.17
291 Great Vessel: Discontinuous PAs	1	0	0.00	0.02	16	1	6.25	0.31
292 Great Vessel: Bronchial PA Blood Flow (MAPCA)	.	.	.	.	24	5	20.83	0.46
293 Great Vessel: Isolated LSVC	1	0	0.00	0.02	9	1	11.11	0.17
294 Great Vessel: Bilateral SVCs	.	.	.	.	34	0	0.00	0.66
295 Great Vessel: Azygous/Hemiazygous Continuous IVC	.	.	.	.	13	1	7.69	0.25
296 Great Vessel: Other Great Vessel Anomalies	6	0	0.00	0.12	29	1	3.45	0.56
300 Coronary Artery: Coronary Artery Fistula	3	0	0.00	0.06	9	1	11.11	0.17
301 Coronary Artery: Coronary Artery Sinusoids	.	.	.	.	1	1	100.00	0.02
302 Coronary Artery: Coronary Artery Stenosis	1	0	0.00	0.02	4	1	25.00	0.08
304 Coronary Artery: Anomalous Origin Coronary Artery	45	0	0.00	0.87	72	1	1.39	1.39
305 Coronary Artery: Atresia Left Main Coronary Artery	1	0	0.00	0.02	3	0	0.00	0.06
306 Coronary Artery: Atresia Right Main Coronary Artery	.	.	.	.	1	0	0.00	0.02
310 Cardiac Rhythm: Supraventricular tachycardia	.	.	.	.	7	0	0.00	0.14
312 Cardiac Rhythm: Sinus bradycardia	2	0	0.00	0.04	7	1	14.29	0.14
313 Cardiac Rhythm: Heart Block	1	0	0.00	0.02	15	3	20.00	0.29
320 Cardiomyopathies: Hypertrophic: Left Ventricle	4	0	0.00	0.08	18	0	0.00	0.35
321 Cardiomyopathies: Hypertrophic: Right Ventricle	.	.	.	.	21	2	9.52	0.41
322 Cardiomyopathies:Dilated	.	.	.	.	6	2	33.33	0.12
398 Other Diagnoses NOT Listed	6	0	0.00	0.12	18	0	0.00	0.35

APPENDIX 2

Patient groups derived from analysis of pediatric congenital cardiac surgery cases in New York State, 2006-2009 discharges.

The table below lists the 11 patient groups derived from the analysis of 2006-2009 pediatric congenital cardiac surgery. The following information is included for each of the 11 groups: the number of cases; the prevalence, or percent of all cases accounted for by that group; the number of deaths within the group; and the observed mortality rate within the group.

For univentricular patients, a high-risk patient was one who had one of the following diagnoses, with or withourt any other diagnoses: Hypoplastic Left Ventricle, Classical HLHS or any other (NYS Diagnosis Codes 190 and 191, respectively). Patients with a univentricular heart that did not have one of these diagnoses were classified as moderate-risk. No univentricular patients are associated with a low-risk diagnosis.

For biventricular patients, a high risk patient was one who had at least one of the following diagnoses, with or withourt any other diagnoses: Anomalies of Pulmonary Veins - Total Anomalous Return, Infracardiac (code 103); Anomalies of Pulmonary Ventricular Outflow Tract, Main Pulmonary Artery Atresia (code 207); Tetralogy of Fallot, with Pulmonary Valve Atresia or Absent Pulmonary Valve Syndrome (codes 241 - 242); Double Outlet Right Ventricle with Subaortic, Subpulmonic or Uncommitted Ventricular Septal Defect (Codes 270-272).

A low risk patient was one whose only reported diagnosis was one of the following: Anomalies of the Atrial Septum - Secundum ASD, Single Atrium, Unroofed Coronary Sinus, Sinus Venosus ASD, or Patent Foramen Ovale (codes 110-114); Anomalies of Ventricular Septum / Ventricular Septal Defect (VSD)- Perimembranous , Doubly committed, Inlet, Muscular or Multiple (codes 150-154); Atrioventricular Septal Defects (AVSDs)- Partial Primum ASD or Complete AVSD- Balanced (codes 160-161); Anomalies of the Pulmonary Ventricular Outflow Tract - Pulmonary Valve Stenosis, Subvalvular/ Infundibular Pulmonary Stenosis or Double Chamber Right Ventricle (codes 201-203); Anomalies of Aortic Ventricular Outflow Tract - Valvular Aortic Stenosis, Discrete Subbvalvular Aortic Stenosis, or Aortic Valve Regurgitation (codes 210-211, 231); Great Vessel Anomalies - Aortic Coarctation (code 284). A patient with Anomalies of Pulmonary Veins - Partial Anomalous Return (code 100) in conjunction with Anomalies of Atrial Septum - Sinus Venosus ASD (code 113) was also at low risk. Otherwise, patients with more than one diagnosis, even more than one low-risk diagnosis, were not considered low risk.

Patients classified as having moderate-risk diagnoses were those with any diagnosis not listed as high- or low-risk above and those with more than one low-risk diagnosis.

Patient group	Cases	Prevalence (%)	No. of deaths	Mortality rate (%)
Univentricle, age < 30 days				
High-risk	188	3.64	32	17.02
Moderate-risk	117	2.27	18	15.38
Univentricle, age 1 – 12 months				
Moderate to High-risk	289	5.60	11	3.81
Univentricle, age >= 1 year				
Moderate to High-risk	316	6.12	4	1.27
Biventricle, age < 30 days				
High-risk	144	2.79	22	15.28
Moderate-risk	634	12.28	35	5.52
Low-risk	73	1.41	1	1.37
Biventricle, age >= 1 month				
High-risk, 1 – 12 months	161	3.12	14	8.70
Moderate-risk, 1 – 12 months	1106	21.43	20	1.81
Moderate to High-risk, >= 1 year	1061	20.55	13	1.23
Low risk	1073	20.79	3	0.28
Total	5162	–	173	3.35

APPENDIX 3

2006-2009 Multivariable (Logistic Regression) Model for Pediatric Congenital Cardiac Surgery In-Hospital Mortality

The significant pre-procedural risk factors for in-hospital mortality following pediatric congenital cardiac surgery in 2006-2009 are presented in the table below.

Roughly speaking, the odds ratio for a risk factor represents the number of times a patient is more likely to die in the hospital during or after cardiac surgery than a patient without the risk factor, all other risk factors being the same. For example, a patient with ventilator dependence prior to surgery has an odds of dying in the hospital that is 1.683 times the odds for a patient who is not ventilator dependent prior to surgery, assuming the patients look identical with regard to all other significant risk factors.

Age/birthweight is divided into five categories: Less than 30 days with and without birthweight less than 2000g, 30 days to 1 year with and without low birthweight, and 1 year or older. The last category is referred to as the reference category. The odds ratios for the other age and birthweight categories are all relative to patients who are at least 1 year old. For example, a patient who is less than 30 days old at the time of surgery and weighed less than 2000g at birth is 21.21 times more likely to die in the hospital during or after cardiac surgery than a patient who is 1 year or older, with all the other significant risk factors the same.

The odds ratio for univentricular disease is relative to biventricular disease. High, medium and low-risk diagnoses are classified the same way as described in Appendix 2. The reference for medium or high risk diagnoses is low risk diagnoses. All of the other factors in the model are interpreted in the same way as pre-op ventilator dependence as described above.

		Logistic Regression		
Patient Risk Factor	**Prevalence (%)**	**Coefficient**	**P-value**	**Odds Ratio**
Age				
Greater than 1 year	41.04	— Reference —		1.000
Less than 30 days				
With Birthweight < 2000g	1.07	3.0545	<.0001	21.210
With Birthweight 2000g or more	21.33	1.4922	<.0001	4.447
30 days – 1 year				
With Birthweight < 2000g	3.20	1.6493	<.0001	5.203
With Birthweight 2000g or more	33.36	0.5577	0.0667	1.747
Type of Defect				
Biventricular	82.37	— Reference —		1.000
Univentricular	17.63	0.4426	0.0222	1.557
Risk Associated with Diagnosis				
Low	22.21	— Reference —		1.000
Medium	60.03	1.3242	0.0112	3.759
High	17.76	2.0460	<.0001	7.737
Comorbidities				
Major Extracardiac Anomalies	9.42	0.5649	0.0082	1.759
Positive Blood Cultures	1.51	0.8848	0.0120	2.423
Pre-existing Neurologic Abnormality	3.39	0.8300	0.0042	2.293
Pre-op Ventilator Dependence	16.49	0.5207	0.0091	1.683
Pulmonary Hypertension	11.70	0.4438	0.0314	1.559
Renal Failure Requiring Dialysis	0.41	1.3483	0.0221	3.851
Severe Cyanosis or Hypoxia	15.50	0.4673	0.0090	1.596

Intercept = -6.3715
C-Statistic = 0.854

APPENDIX 4

Criteria Used in Reporting Significant Risk Factors (2006-2009) Based on Documentation in the Medical Record

Comorbidity	Criteria
Major Extra-cardiac Anomalies	Examples include but are not limited to: Non-Down's Syndrome chromosomal abnormalities, DiGeorge's Syndrome, Cystic Fibrosis, Marfan's Syndrome, Sickle Cell Anemia, Blood Dyscrasia, Omphalocele, Hypoplastic lung, Tracheo-esophageal (TE) fistula, Diaphragmatic hernia
Positive Blood Cultures within 2 Weeks of Surgery	Code if the patient had positive blood cultures that are documented in the medical record, occurring within 2 weeks prior to surgery.
Pre-existing Neurologic Abnormality	Pre-existing neurological abnormality includes but is not limited to: Documented intracranial bleed, Hydrocephalus, Arterial venous malformation, Cerebral vascular accident (CVA), Seizure disorders
Pre-op Ventilator Dependence	The patient was ventilator dependent during the same admission or within 14 days prior to surgery.
Pulmonary Hypertension	Code when systolic pressure reaches > 50% systemic or when elevated pulmonary vascular resistance exists.
Renal Failure Requiring Dialysis	Code if the patient received either continuous or intermittent hemodialysis or peritoneal dialysis within 14 days prior to surgery.
Severe Cyanosis or Severe Hypoxia	Code if any of the following are present and documented in the patient's medical record: Pulse oximetry saturation <70% Resting PO_2 < 35mmHg Arterial saturation <75%.

NYS PEDIATRIC CARDIAC SURGERY CENTERS

Albany Medical Center Hospital
New Scotland Avenue
Albany, New York 12208

*** Children's Hospital, Buffalo
219 Bryant Street
Buffalo, New York 14222

Columbia Presbyterian Medical Center –
NY Presbyterian
161 Fort Washington Avenue
New York, New York 10032

Long Island Jewish Medical Center
270-05 76th Avenue
New Hyde Park, New York 11040

Montefiore Medical Center –
Henry & Lucy Moses Division
111 East 210th Street
Bronx, New York 11219

Mount Sinai Medical Center
One Gustave L. Levy Place
New York, New York 10019

NYU Hospitals Center
550 First Avenue
New York, New York 10016

Strong Memorial Hospital
601 Elmwood Avenue
Rochester, New York 14642

*** University Hospital at Stony Brook
SUNY Health Science Center@ Stony Brook
Stony Brook, New York 11794-8410

University Hospital Upstate
Medical Cente
750 East Adams Street
Syracuse, New York 13210

Weill-Cornell Medical Center -
NY Presbyterian
525 East 68 th Street
New York, New York 10021

Westchester Medical Center
Grasslands Reservation
Valhalla, New York 10595

*** Not currently an active pediatric cardiac surgery program.

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