Pediatric Congenital Cardiac Surgery

in New York State

2002-2005

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 second report of risk-adjusted outcomes for pediatric cardiac surgery in New York State. We are the only state in the country 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. While the condition is not common, it is estimated that about 1 in every 125 infants born suffers a serious defect. More than 35 different types of congenital heart defects have been identified. Until recent years, many of these 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, 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 New York State 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 Cardiac Advisory Committee for their efforts in developing and refining this remarkable cooperative quality improvement initiative. The Department of Health will continue to work in partnership with hospitals and physicians to ensure the continued high quality of pediatric congenital heart surgery available in New York State.

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 Department of Health and the Cardiac Advisory Committee 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 New York State.

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 several years. Detailed statistical analyses of the information received from the study have been conducted under the guidance of the New York State Cardiac Advisory Committee, 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 Interventions (PCI) 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 2002-2005 data, is the second report. This report differs from the first report in that the information contained in the pediatric surgical data form for each patient is more comprehensive than it was at the time of the last report. Specifically, multiple pediatric congenital diagnoses are now coded for each patient, whereas the previous data form allowed for only a single diagnosis to be coded.

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 2005. 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, 2002 and December 31, 2005 are included in these analyses. Patients with any non-congenital cardiac disease and those who received a heart 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 15 New York State hospitals with approval to perform cardiac surgery on pediatric patients.

RISK-ADJUSTMENT FOR ASSESSING PROVIDER PERFORMANCE

Hospital performance is an important factor that directly relates to patient outcomes. 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 when assessing performance because different hospitals 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 New York State Department of Health 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 New York State where pediatric cardiac surgery is performed provide information to the Department of Health 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 are entered into a computer, and sent to the Department of Health for analysis, along with information about the hospital, physician, procedure performed, and the patient's status at discharge. Data are verified through the review of unusual reporting frequencies, cross-matching of pediatric cardiac surgery data with other Department of Health 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.

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 from the method used in the first report in that the information contained in the pediatric surgical data form for each patient contains multiple pediatric congenital diagnoses, whereas the previous data form allowed for only a single diagnosis to be coded. Consequently, as a result of the large number of combinations of diagnoses among patients, it was decided to group patients initially on the basis of important determinants of mortality.

Two very important determinants of a patient's mortality in pediatric cardiac surgery are the patient's age and whether there are one or two diseased ventricles (whether the patient has univentricular disease or biventricular disease, respectively). Age was represented in three ways: younger than 30 days, one to 12 months, and 1 year and older. This resulted in six groups based on age and number of diseased ventricles.

The patient's pediatric congenital diagnoses at admission are also very important factors in the patient's risk profile. Since there were large differences in mortality rates within many of the age/number of diseased ventricles groups, these groups were further subdivided into two or three subgroups based on the mortality rates associated with the patient's various diagnoses.

This process resulted in the creation of 14 groups based on age, number of ventricles and severity of diagnoses (high, medium, low). These groups and their mortality rates are presented in Appendix 1. Patients' diagnoses and their mortality rates with and without the presence of other diagnoses are presented in Appendix 2. In addition to these 14 groups, patients have been categorized according to whether or not they have each of a set of comorbidities that were found on the basis of the data to be significant predictors of inpatient mortality. Significant comorbidities include ventilator dependence during same admission or within 14 days prior to surgery, major extracardiac anomalies, pre-existing neurologic abnormality, and pneumonia at the time of surgery. The coding criteria for these comorbidities are presented in Appendix 3.

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 expected mortality rate 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 cases 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 risk-adjusted mortality rate 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 risk-adjusted mortality rate, the observed mortality rate is divided by the hospital's expected mortality rate. 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 (4.08 for 2002-2005) to obtain the hospital's risk-adjusted rate.

Interpreting the Risk-Adjusted Mortality Rate

If the risk-adjusted mortality rate is lower than the statewide mortality rate, the hospital has a better performance than the State as a whole; if the risk-adjusted mortality rate is 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 risk-adjusted mortality rate 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 Department of Health 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 New York State data system has been reviewed by practicing physicians in the field and is updated continually.

How This Contributes to Quality Improvement

The goal of the Department of Health and the Cardiac Advisory Committee is to improve the quality of care for pediatric patients with congenital cardiac anomalies in New York State. Providing hospitals in New York State with data about their own outcomes for patients with specific congenital diagnoses allows them to examine the quality of the care provided for these patients and to identify opportunities to improve care.

The information collected and analyzed in this program is also given to the Cardiac Advisory Committee, which assists with interpretation and advises the Department of Health regarding hospitals that may need special attention. Committee members have also conducted site visits to particular hospitals, provided recommendations for improved care and, in some cases, have recommended that hospitals obtain expertise from outside consultants to design improvements for their programs.

2002-2005 HOSPITAL OUTCOMES FOR PEDIATRIC CONGENITAL CARDIAC SURGERY

Table 1 presents the 2002-2005 Pediatric Cardiac Surgery results for the 15 hospitals performing congenital heart surgery in pediatric patients in New York State. The table contains, for each hospital, the number of pediatric congenital cardiac procedures performed resulting in discharges between 2002-2005, the number of in-hospital deaths, the observed mortality rate, the expected mortality rate based on the statistical model presented in Appendix 4, the risk-adjusted mortality rate, and the 95% confidence interval for the risk-adjusted mortality rate.

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 observed mortality rate by the expected mortality rate, and then multiplying the quotient by the statewide mortality rate (4.08 for all pediatric congenital cardiac surgery patients in 2002-2005).

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 RAMR rates 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.

As indicated in Table 1, the overall mortality for the 5,466 pediatric congenital cardiac surgeries performed at 15 New York State hospitals and discharged between January 1, 2002 and December 31, 2005 was 4.08%. Observed mortality for all pediatric congenital cardiac surgery patients ranged from 0.00% to 6.30%. The range in expected mortality, which measures patient severity of illness, was 0.39% to 7.91%.

The risk-adjusted mortality rates, which are used to measure performance, ranged from 0.00% to 6.86%. One hospital (Long Island Jewish Medical Center) had a risk-adjusted mortality rate that was significantly higher than the statewide rate, and one hospital (Columbia Presbyterian Medical Center) had a risk-adjusted mortality rate that was significantly lower than the statewide rate.

Note on Hospitals Not Performing Pediatric Cardiac Surgery During Entire 2002-2005 Period

Several hospitals did not perform Pediatric Congenital Cardiac Surgery for the entire four-year time period on which this report is based. Bellevue Hospital closed its program in 2000 and re-opened in 2004. The program at Children's Hospital – Buffalo closed in 2000 and re-opened in 2003. Two others, North Shore University Hospital and St. Francis Hospital closed their programs and had no reportable cases for 2003 - 2005.

Table 1: Hospital Observed, Expected, and Risk-Adjusted Mortality Rates (RAMR) for Pediatric Congenital Cardiac Surgery in New York State, 2002-2005 Discharges (Listed Alphabetically by Hospital)

Hospital	Cases	Deaths	OMR	EMR	RAMR	95% CI for RAMR
Albany Medical Center	315	6	1.90	3.96	1.96	(0.72, 4.27)
Bellevue	14	0	0.00	0.44	0.00	(0.00,100.0)
Children's - Buffalo	12	0	0.00	7.91	0.00	(0.00,15.77)
Columbia Presbyterian-NYP	1807	74	4.10	5.26	3.18 **	(2.49, 3.99)
LIJ Medical Center	670	31	4.63	2.75	6.86 *	(4.66, 9.74)
Montefiore - Moses	170	6	3.53	2.24	6.43	(2.35,14.00)
Mount Sinai Hospital	550	23	4.18	3.40	5.01	(3.18, 7.52)
NYU Hospitals Center	326	15	4.60	2.81	6.67	(3.73,11.01)
North Shore Univ Hosp.	41	2	4.88	2.48	8.02	(0.90,28.96)
St. Francis Hosp.	7	0	0.00	0.39	0.00	(0.00,100.0)
Strong Memorial Hospital	533	24	4.50	4.50	4.09	(2.62, 6.08)
Univ. Hosp. - Stony Brook	201	4	1.99	1.55	5.22	(1.41,13.37)
Univ. Hosp. - Upstate	345	18	5.22	4.93	4.32	(2.56, 6.82)
Weill Cornell-NYP	237	5	2.11	2.64	3.27	(1.05, 7.62)
Westchester Medical Center	238	15	6.30	5.43	4.74	(2.65, 7.82)
Total	**5466**	**223**	**4.08**			

* 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

Patient groups used in analysis of pediatric cardiac congenital cases in New York State, 2002-2005 discharges.

The table below lists the 14 patient groups used in the analysis of 2002-2005 pediatric congenital cardiac surgery. The following information is included for each of the 14 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 diagnosis 190; for biventricular patients, a high-risk patient was one who had at least one diagnosis of 103, 207, 241, 242, 270, 271 and 272. A low-risk patient was one who only had one or more diagnoses of 110-114, 150-154, 160-161, 201-203, 210-211, 231 and 284. A patient with 100 in conjunction with 113 was also at low-risk. A list of the name of each diagnosis associated with the codes above is included in Appendix 2.

Patient group	Cases	Prevalence (%)	No. of deaths	Mortality rate (%)
Univentricle, age < 30 days				
High-risk	129	2.36	35	27.13
Low- to moderate-risk	192	3.51	30	15.63
Univentricle, age 1 – 12 months				
High-risk	81	1.48	6	7.41
Low- to moderate-risk	208	3.81	8	3.85
Univentricle, age >= 1 year				
High-risk	72	1.32	5	6.94
Low- to moderate-risk	259	4.74	4	1.54
Biventricle, age < 30 days				
High-risk	174	3.18	19	10.92
Moderate-risk	687	12.57	57	8.30
Low-risk	83	1.52	4	4.82
Biventricle, age >= 1 month				
High-risk, 1 – 12 months	172	3.15	10	5.81
Moderate-risk, 1–12 months	1161	21.24	28	2.41
High-risk, >= 1 year	187	3.42	3	1.60
Moderate-risk, >= 1 year	1057	19.34	12	1.14
Low risk	1004	18.37	2	0.20
Total	**5466**	**–**	**223**	**4.08**

APPENDIX 2

Pediatric Congenital Cardiac Diagnoses in New York State, 2002-2005

The following table is a complete list of all congenital diagnoses that were reported for pediatric congenital cardiac surgery patients between 2002-2005. 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 2002-2005 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.

Appendix 2. Pediatric Congenital Cardiac Diagnoses in New York State, 2002-2005.

Code Diagnosis	Sole Diagnosis				Any Diagnosis			
	Cases	Deaths	OMR	Prevalence	Cases	Deaths	OMR	Prevalence
10 Atrial Situs: Situs Inversus	.	.	.	.	15	1	6.67	0.27
11 Atrial Situs: Situs Ambiguous/Heterotaxy Syndrome	.	.	.	.	74	11	14.86	1.35
20 Cardiac Position: Dextrocardia	.	.	.	.	49	4	8.16	0.90
21 Cardiac Position: Mesocardia	.	.	.	.	8	2	25.00	0.15
100 Pulmonary Veins: Partial Anomalous Return	20	0	0.00	0.37	128	1	0.78	2.34
101 Pulmonary Veins: Total Anomalous Return: Supracardiac	15	0	0.00	0.27	65	9	13.85	1.19
102 Pulmonary Veins: Total Anomalous Return: Cardiac	9	1	11.11	0.16	34	2	5.88	0.62
103 Pulmonary Veins: Total Anomalous Return: Infracardiac	4	1	25.00	0.07	34	5	14.71	0.62
104 Pulmonary Veins: Total Anomalous Return: Mixed	3	1	33.33	0.05	18	6	33.33	0.33
105 Pulmonary Veins: Pulmonary Vein Stenosis	10	0	0.00	0.18	31	5	16.13	0.57
106 Pulmonary Veins: Cor Triatrialum	6	0	0.00	0.11	16	1	6.25	0.29
110 Atrial Septum: Secundum ASD	260	0	0.00	4.76	895	24	2.68	16.37
111 Atrial Septum: Single Atrium	2	0	0.00	0.04	15	1	6.67	0.27
112 Atrial Septum: Unroofed Coronary Sinus	2	0	0.00	0.04	11	0	0.00	0.20
113 Atrial Septum: Sinus Venosus ASD	30	0	0.00	0.55	123	1	0.81	2.25
114 Atrial Septum: PFO	1	0	0.00	0.02	313	13	4.15	5.73
120 Tricuspid: Ebsteins Anomaly	8	0	0.00	0.15	37	7	18.92	0.68
121 Tricuspid: Tricuspid Stenosis	.	.	.	.	7	0	0.00	0.13
122 Tricuspid: Tricuspid Regurgitation	5	0	0.00	0.09	91	8	8.79	1.66
123 Tricuspid: Straddling Tricuspid Valve	.	.	.	.	5	0	0.00	0.09
130 Mitral: Supravalvular Mitral Stenosis	4	0	0.00	0.07	12	0	0.00	0.22
131 Mitral: Valvular Mitral Stenosis	7	0	0.00	0.13	50	2	4.00	0.91
132 Mitral: Subvalvular Mitral Stenosis	.	.	.	.	5	1	20.00	0.09
133 Mitral: Mitral Regurgitation	46	1	2.17	0.84	188	4	2.13	3.44
134 Mitral: Straddling Mitral Valve	.	.	.	.	11	0	0.00	0.20
135 Mitral: Papillary Muscle Abnormality	.	.	.	.	4	0	0.00	0.07
140 Common AV Valve: Stenosis	2	0	0.00	0.04	8	1	12.50	0.15
141 Common AV Valve: Regurgitation	2	0	0.00	0.04	41	0	0.00	0.75
142 Common AV Valve: Malaligned	1	1	100.00	0.02	6	3	50.00	0.11
150 Ventricular Septum: Perimembranous VSD	198	0	0.00	3.62	830	26	3.13	15.18
151 Ventricular Septum: Doubly committed VSD	17	0	0.00	0.31	80	4	5.00	1.46
152 Ventricular Septum: Inlet VSD	12	0	0.00	0.22	69	2	2.90	1.26
153 Ventricular Septum: Muscular VSD	13	1	7.69	0.24	92	7	7.61	1.68
154 Ventricular Septum: Multiple VSDs	16	0	0.00	0.29	68	3	4.41	1.24
160 AVSD: Partial AVSD (Primum ASD)	62	0	0.00	1.13	152	3	1.97	2.78
161 AVSD: Complete AVSD: Balanced	111	1	0.90	2.03	308	10	3.25	5.63
162 AVSD: Complete AVSD: Unbalanced	31	2	6.45	0.57	123	10	8.13	2.25

Appendix 2 (continued): Pediatric congenital cardiac diagnoses in New York State, 2002-2005.

Code	Diagnosis	Sole Diagnosis				Any Diagnosis			
		Cases	Deaths	OMR	Prevalence	Cases	Deaths	OMR	Prevalence
170	Single Ventricle: Double/Common Inlet LV	31	0	0.00	0.57	76	1	1.32	1.39
171	Single Ventricle: Double/Common Inlet RV	4	0	0.00	0.07	21	2	9.52	0.38
172	Single Ventricle: Tricuspid Atresia: With IVS	32	2	6.25	0.59	47	2	4.26	0.86
173	Single Ventricle: Tricuspid Atresia: With VSD	42	1	2.38	0.77	114	4	3.51	2.09
174	Single Ventricle: Tricuspid Atresia: With TGA	11	0	0.00	0.20	30	0	0.00	0.55
175	Single Ventricle: Mitral Atresia	2	0	0.00	0.04	42	6	14.29	0.77
176	Single Ventricle: Indeterminate Ventricle	4	0	0.00	0.07	21	3	14.29	0.38
180	Single Ventricle: Hypoplastic RV: Pulmonary atresia with IVS	32	2	6.25	0.59	86	7	8.14	1.57
181	Single Ventricle: Hypoplastic RV: Other type of hypoplastic RV	16	0	0.00	0.29	65	6	9.23	1.19
190	Single Ventricle: Hypoplastic LV: Classical HLHS	156	25	16.03	2.85	282	46	16.31	5.16
191	Single Ventricle: Hypoplastic LV: Any other Hypoplastic LV	51	3	5.88	0.93	146	15	10.27	2.67
200	Outflow: Pulmonary	4	0	0.00	0.07	14	1	7.14	0.26
201	Outflow: Pulmonary: Pulmonary Valve Stenosis	35	1	2.86	0.64	278	12	4.32	5.09
202	Outflow: Pulmonary: Subvalvular/Infundibular Pulmonary Stenosis	5	0	0.00	0.09	178	4	2.25	3.26
203	Outflow: Pulmonary: Double Chamber Right Ventricle	6	0	0.00	0.11	50	1	2.00	0.91
204	Outflow: Pulmonary: Branch Pulmonary Artery Stenosis	2	0	0.00	0.04	182	12	6.59	3.33
205	Outflow: Pulmonary: Hypoplastic Pulmonary Arteries	.	.	.	.	33	7	21.21	0.60
206	Outflow: Pulmonary: Pulmonary Valve Regurgitation	11	0	0.00	0.20	38	0	0.00	0.70
207	Outflow: Pulmonary: Main Pulmonary Artery Atresia	23	2	8.70	0.42	132	10	7.58	2.41
208	Outflow: Pulmonary: Branch Pulmonary Artery Atresia	2	0	0.00	0.04	17	1	5.88	0.31
210	Outflow: Aortic: Valvular Aortic Stenosis	14	0	0.00	0.26	73	6	8.22	1.34
211	Outflow: Aortic: Subvalvular Aortic Stenosis: Discrete	65	0	0.00	1.19	155	3	1.94	2.84
212	Outflow: Aortic: Subvalvular Aortic Stenosis: Long Segment/Tunnel	3	0	0.00	0.05	45	3	6.67	0.82
220	Outflow: Aortic: Supravalvular Aortic Stenosis	9	0	0.00	0.16	37	3	8.11	0.68
230	Outflow: Aortic: Aortic Valve Atresia	1	0	0.00	0.02	8	2	25.00	0.15
231	Outflow: Aortic: Aortic Valve Regurgitation	24	0	0.00	0.44	144	2	1.39	2.63
232	Outflow: Aortic: Aorto-Ventricular Tunnel	1	0	0.00	0.02	1	0	0.00	0.02
240	TOF: RV-PA Continuity	233	3	1.29	4.26	506	13	2.57	9.26
241	TOF: TOF with Pulmonary Valve Atresia	113	6	5.31	2.07	249	13	5.22	4.56
242	TOF: Absent Pulmonary Valve Syndrome	11	2	18.18	0.20	24	3	12.50	0.44
250	Truncus Arterious: Type I	20	1	5.00	0.37	49	4	8.16	0.90
251	Truncus Arterious: Type II	3	0	0.00	0.05	18	3	16.67	0.33
252	Truncus Arterious: Type III	.	.	.	.	4	0	0.00	0.07
260	TGA: D-TGA	43	2	4.65	0.79	387	18	4.65	7.08
261	TGA: Congenitally Corrected Transposition	6	0	0.00	0.11	74	4	5.41	1.35
270	Double Outlet RV: Subaortic VSD	14	1	7.14	0.26	102	4	3.92	1.87
271	Double Outlet RV: Subpulmonic VSD	3	0	0.00	0.05	41	3	7.32	0.75
272	Double Outlet RV: Uncommitted VSD	2	0	0.00	0.04	45	2	4.44	0.82
273	Double Outlet RV: Doubly Committed VSD	3	0	0.00	0.05	17	0	0.00	0.31
274	Double Outlet RV: Restrictive VSD	1	0	0.00	0.02	11	1	9.09	0.20
280	Great Vessel: Aortopulmonary Window	4	1	25.00	0.07	16	1	6.25	0.29
281	Great Vessel: Patent Ductus Arteriosus	114	7	6.14	2.09	958	62	6.47	17.53
282	Great Vessel: Origin of L/R PA from Aorta	3	0	0.00	0.05	10	1	10.00	0.18
283	Great Vessel: Sinus of Valsalva Aneurysm/Fistula	3	0	0.00	0.05	6	0	0.00	0.11
284	Great Vessel: Aortic Coarctation	173	3	1.73	3.17	522	26	4.98	9.55
285	Great Vessel: Aortic Interruption	5	0	0.00	0.09	77	5	6.49	1.41
286	Great Vessel: Aortic Aneurysm: Ascending	1	0	0.00	0.02	8	0	0.00	0.15

Appendix 2 (continued): Pediatric congenital cardiac diagnoses in New York State, 2002-2005.

Code Diagnosis	Sole Diagnosis				Any Diagnosis			
	Cases	Deaths	OMR	Prevalence	Cases	Deaths	OMR	Prevalence
287 Great Vessel: Aortic Aneurysm: Descending	.	.	.	.	4	0	0.00	0.07
288 Great Vessel: Aortic Aneurysm: Transverse	.	.	.	.	3	0	0.00	0.05
289 Great Vessel: Vascular Ring	44	0	0.00	0.80	77	0	0.00	1.41
290 Great Vessel: Origin of LPA from RPA (PA sling)	1	0	0.00	0.02	5	1	20.00	0.09
291 Great Vessel: Discontinuous PAs	.	.	.	.	24	2	8.33	0.44
292 Great Vessel: Bronchial PA Blood Flow (MAPCA)	.	.	.	.	12	0	0.00	0.22
293 Great Vessel: Isolated LSVC	.	.	.	.	11	0	0.00	0.20
294 Great Vessel: Bilateral SVCs	.	.	.	.	24	3	12.50	0.44
295 Great Vessel: Azygous/Hemiazygous Continuous IVC	.	.	.	.	8	0	0.00	0.15
296 Great Vessel: Other Great Vessel Anomalies	7	0	0.00	0.13	25	2	8.00	0.46
300 Coronary Artery: Coronary Artery Fistula	4	0	0.00	0.07	4	0	0.00	0.07
301 Coronary Artery: Coronary Artery Sinusoids	.	.	.	.	1	0	0.00	0.02
302 Coronary Artery: Coronary Artery Stenosis	.	.	.	.	2	0	0.00	0.04
304 Coronary Artery: Anomalous Origin Coronary Artery	14	0	0.00	0.26	42	2	4.76	0.77
310 Cardiac Rhythm: Supraventricular tachycardia	.	.	.	.	17	2	11.76	0.31
312 Cardiac Rhythm: Sinus bradycardia	.	.	.	.	1	0	0.00	0.02
313 Cardiac Rhythm: Heart Block	1	1	100.00	0.02	12	2	16.67	0.22
320 Cardiomyopathies: Hypertrophic: Left Ventricle	2	0	0.00	0.04	17	2	11.76	0.31
321 Cardiomyopathies: Hypertrophic: Right Ventricle	1	0	0.00	0.02	30	3	10.00	0.55
322 Cardiomyopathies:Dilated	.	.	.	.	6	0	0.00	0.11
398 Other Diagnoses NOT Listed	1	0	0.00	0.02	11	2	18.18	0.20
Statewide Total	**.**	**.**	**.**	**.**	**5466**	**223**	**4.08**	**100.00**

APPENDIX 3

Criteria Used in Reporting Significant Risk Factors (2002-2005) Based on Documentation in the Medical Record

Comorbidity	Criteria
Ventilator Dependence	The patient was ventilator dependent during the same admission or within 14 days prior to surgery.
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
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
Pneumonia at Time of Surgery	As evidenced by: Chest X-ray with infiltrate *and at least **ONE** of the following:* • temperature greater than 101°F (38.5°C) • white blood count greater than 12,000 • positive blood culture/viral titer

APPENDIX 4

2002-2005 Multivariable (Logistic Regression) Model for Pediatric Cardiac Surgery In-Hospital Mortality

The significant pre-procedural risk factors for in-hospital mortality following pediatric cardiac surgery in 2002-2005 are presented in the table below.

The odds ratios for patient groups are relative to the total patient population with a mortality rate of 4.08%. For example, for univentricular patients aged younger than 30 days who had high-risk diagnoses, the odds ratio of 6.505 means that the risk of dying in hospital for this group of patients is 6.505 times the risk of the total patient population, all significant comorbidities being the same.

The odds ratio for each comorbidity is relative to patients without that comorbidity. For example, a patient with ventilator dependence prior to surgery has an odds of dying in the hospital that is 2.048 times the odds for a patient who is not ventilator dependent prior to surgery, assuming the patients are in the same diagnosis group and have the same other comorbidities among the ones in the table below.

Appendix 4. Multivariable risk factor equation for pediatric congenital cardiac surgery in-hospital mortality in New York State, 2002-2005.

		Logistic Regression		
Patient Risk Factor	**Prevalence (%)**	**Coefficient**	**Odds ratio**	**P-value**
Patient groups				
Univentricle, age < 30 days				
High-risk	2.36	1.8725	6.505	<.0001
Low- to moderate-risk	3.51	1.1640	3.203	<.0001
Univentricle, age 1 – 12 months				
High-risk	1.48	0.8480	2.335	0.0390
Low- to moderate-risk	3.81	0.0103	1.010	0.9769
Univentricle, age >= 1 year				
High-risk	1.32	0.7408	2.098	0.1000
Low- to moderate-risk	4.74	-0.8523	0.426	0.0780
Biventricle, age < 30 days				
High-risk	3.18	0.7902	2.204	0.0026
Moderate-risk	12.57	0.4623	1.588	0.0108
Low-risk	1.52	-0.2728	0.761	0.5894
Biventricle, age >= 1 month				
High-risk, 1 – 12 months	3.15	0.4762	1.610	0.1426
Moderate-risk, 1 – 12 months	21.24	-0.5180	0.596	0.0138
High-risk, >= 1 year	3.42	-0.7661	0.465	0.1672
Moderate-risk, >= 1 year	19.34	-1.1186	0.327	0.0001
Low risk	18.37	-2.8366	0.059	<.0001
Comorbidities				
Pre-op ventilator dependence	16.39	0.7171	2.048	<.0001
Major extracardiac anomalies	9.20	0.8861	2.426	<.0001
Pre-existing neurologic abnormality	2.65	0.9515	2.590	0.0009
Pneumonia at time of surgery	0.81	1.1960	3.307	0.0111

Intercept = -3.5407

C-Statistic = 0.829

NYS PEDIATRIC CARDIAC SURGERY CENTERS

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Albany, New York 12208

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New York, New York 10016

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Center – NY Presbyterian
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Grasslands Reservation
Valhalla, New York 10595

* This program closed in 2000 and reopened in 2004
** This program closed in 2000 and reopened in 2003
*** These programs are currently not active.

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Department of Health

01/07