# Pediatric Congenital Cardiac Surgery

# in New York State

## *1997-1999*

**New York State Department of Health**
**February 2004**

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# MESSAGE FROM THE COMMISSIONER

I am 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 a major step forward in our ongoing efforts to provide comprehensive monitoring and assessment information for both patients and providers. This is the first report of risk-adjusted outcomes for pediatric cardiac surgery in New York State, and 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.

I extend my 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 diagnosis, 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. This is the first time Pediatric Congenital Cardiac Surgery data have been released.

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 1999. Important changes may have taken place in some hospitals since that time.

## PATIENT POPULATION

All pediatric patients (age <18 years) undergoing congenital cardiac surgery in New York State hospitals who were discharged between January 1, 1997 and December 31, 1999 are included in these analyses. Observed, expected, and risk-adjusted mortality rates are reported for patients undergoing congenital cardiac surgery in each of the 16 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. Approximately 22 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, patient diagnosis on admission, 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.

Another important factor in the patient's risk profile is the diagnosis at admission. There are approximately 55 different diagnoses that are collected for pediatric patients, all of which have a varying degree of risk associated with them. To take this relative risk into account, a reference group consisting of lower risk diagnoses was created. This reference group (listed in Appendix 2) consists of all diagnoses that have a post-surgical mortality rate less than or equal to 2.00%. The remaining diagnoses are then compared individually to the reference group and their relative risk is used in addition to demographic and clinical factors to determine the patient's risk profile. For purposes of this report each patient has had only one of the listed diagnoses reported.

The statistical analyses conducted by the Department of Health consist of determining which of the risk factors and diagnoses collected are significantly related to in-hospital death. The significant risk factors and diagnoses are weighted and used to predict the chance that each patient will have of dying in the hospital given his or her specific characteristics.

### 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 (5.35 for 1997-1999) 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 asterisk, 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.

## 1997-1999 HOSPITAL OUTCOMES FOR PEDIATRIC CONGENITAL CARDIAC SURGERY

Table 1 presents the 1997-1999 Pediatric Cardiac Surgery results for the 16 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 between 1997-1999, the number of in-hospital deaths, the observed mortality rate, the expected mortality rate based on the statistical model presented in Appendix 3, 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 (5.35 for all pediatric congenital cardiac surgery patients in 1997-1999).

**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 indentifies 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 4,710 pediatric congenital cardiac surgeries performed at 16 New York State hospitals and discharged between January 1, 1997 and December 31, 1999 was 5.35%. Observed mortality for all pediatric congenital cardiac surgery patients ranged from 0.00% to 11.96%. The range in expected mortality, which measures patient severity of illness, was 1.31% to 7.95%.

The risk-adjusted mortality rates, which are used to measure performance, ranged from 0.00% to 17.08%. Two hospitals (University Hospital of Brooklyn and Westchester Medical Center) had risk-adjusted mortality rates that were 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.

**Table 1:** Hospital Observed, Expected, and Risk-Adjusted Mortality Rates (RAMR) for Pediatric Congenital Cardiac Surgery in New York State, 1997-1999 Discharges (Listed Alphabetically by Hospital)

| Hospital | Cases | Deaths | OMR | EMR | RAMR | 95% CI for RAMR |
|---|---|---|---|---|---|---|
| Albany Medical Center | 120 | 2 | 1.67 | 1.69 | 5.28 | (0.59, 19.07) |
| Bellevue | 17 | 0 | 0.00 | 2.36 | 0.00 | (0.00, 49.00) |
| Children's Hosp.-Buffalo | 361 | 22 | 6.09 | 5.19 | 6.28 | (3.93, 9.51) |
| Columbia Presbyterian-NYP | 1076 | 62 | 5.76 | 7.95 | 3.88** | (2.97, 4.97) |
| LIJ Medical Center | 243 | 16 | 6.58 | 4.09 | 8.62 | (4.92, 14.00) |
| Montefiore - Moses | 240 | 10 | 4.17 | 4.19 | 5.33 | (2.55, 9.80) |
| Mount Sinai | 511 | 33 | 6.46 | 6.65 | 5.19 | (3.57, 7.29) |
| North Shore | 472 | 22 | 4.66 | 4.11 | 6.07 | (3.80, 9.19) |
| NYU Hospitals Center | 317 | 15 | 4.73 | 4.90 | 5.17 | (2.89, 8.53) |
| St. Francis | 143 | 3 | 2.10 | 1.78 | 6.32 | (1.27, 18.46) |
| Strong Memorial | 199 | 18 | 9.05 | 5.69 | 8.51 | (5.04, 13.45) |
| Univ. Hosp. at Stony Brook | 53 | 2 | 3.77 | 1.31 | 15.41 | (1.73, 55.65) |
| Univ. Hosp. of Brooklyn | 92 | 11 | 11.96 | 3.75 | 17.08* | (8.52, 30.56) |
| Univ. Hosp. - Upstate | 368 | 14 | 3.80 | 6.08 | 3.35 | (1.83, 5.62) |
| Weill Cornell-NYP | 209 | 5 | 2.39 | 3.23 | 3.97 | (1.28, 9.26) |
| Westchester Medical Center | 289 | 17 | 5.88 | 3.23 | 9.74* | (5.67, 15.60) |
| **Total** | **4710** | **252** | **5.35** | | | |

* 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.

# Criteria Used in Reporting Significant Risk Factors (1997-1999)

## Based on Documentation in Medical Record

| Patient Risk Factor | Criteria |
|---|---|
| **Co-morbidities** | |
| • Arterial pH < 7.25 | Determined immediately pre-op |
| • Pulmonary Hypertension | A systolic pressure > 50% systemic or elevated pulmonary vascular resistance |
| • Severe Cyanosis | Pulse oximetry < 70% or resting $P0_2$ < 35 mmHg or arterial saturation < 75% |
| • Significant Extra Cardiac Anomalies | Examples include but are not limited to: Non-Downs Syndrome chromosomal abnormalities, DiGeorge's Syndrome, Cystic Fibrosis, Marfan Syndrome, Sickel Cell Anemia, Blood Dyscrasia, Omphaloceal, Hypoplastic Lung, Tracheo-Esophageal (TE) Fistula, Diaphragmatic Hernia |
| • Ventilator Dependence | Any ventilator dependence during this admission or whithin 14 days prior to surgery |

# APPENDIX 1

## All Pediatric Congenital Cardiac Diagnoses in New York State, 1997-1999

The following table is a complete list of all congenital diagnoses that were reported for pediatric cardiac surgery patients between 1997-1999. 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, the crude or observed mortality rate, and the percent of all patients operated on between 1997-1999 that had each diagnosis.

**Appendix 1:** All pediatric congenital cardiac diagnoses in New York State, 1997-1999.

| Diagnosis | # of Cases | # of Deaths | Crude Mort. Rate | % of All Cases |
|---|---|---|---|---|
| Patent Ductus Arteriosus and Weight >1500 g | 245 | 4 | 1.63 | 5.20 |
| Atrial Septal Defect, Secundum | 549 | 2 | 0.36 | 11.66 |
| Atrial Septal Defect, Primum | 29 | 0 | 0.00 | 0.62 |
| Sinus Venosus Defect | 47 | 0 | 0.00 | 1.00 |
| Other Partial Anomalous Pulmonary Connection (PAPVC) | 20 | 0 | 0.00 | 0.42 |
| Atrial Septal Defect and PAPVC | 43 | 0 | 0.00 | 0.91 |
| Atrial Septal Defect and Mitral Valve Anomaly | 51 | 2 | 3.92 | 1.08 |
| Total Anomalous Pulmonary Venous Connection | 104 | 14 | 13.46 | 2.21 |
| Cor Triatrialum | 4 | 0 | 0.00 | 0.08 |
| Complete Atrioventricular Canal Defect | 254 | 12 | 4.72 | 5.39 |
| Paramembranous Ventricular Septal Defect (VSD) | 409 | 3 | 0.73 | 8.68 |
| Subpulmonary Ventricular Septal Defect | 30 | 0 | 0.00 | 0.64 |
| Other Single Ventricular Septal Defect | 100 | 2 | 2.00 | 2.12 |
| Multiple Ventricular Septal Defect | 32 | 3 | 9.38 | 0.68 |
| Ventricular Septal Defect and Aortic Incompetence | 39 | 0 | 0.00 | 0.83 |
| VSD with Straddling or Overriding Tricuspid Valve | 11 | 2 | 18.18 | 0.23 |
| Aneurysm of Sinus Valsalva | 3 | 0 | 0.00 | 0.06 |
| Aortic-Ventricular Tunnel | 1 | 0 | 0.00 | 0.02 |
| Tetrology of Fallot | 387 | 10 | 2.58 | 8.22 |
| Tetrology of Fallot with Pulmonary Atresia | 179 | 13 | 7.26 | 3.80 |
| Tetrology of Fallot with Absent Pulmonary Valve | 18 | 2 | 11.11 | 0.38 |
| Tetrology of Fallot with Other Major Cardiac Defect | 64 | 3 | 4.69 | 1.36 |
| Pulmonary Valve Stenosis | 53 | 0 | 0.00 | 1.13 |
| Pulmonary Atresia with Intact Ventricular Septum | 96 | 7 | 7.29 | 2.04 |
| Tricuspid Atresia | 128 | 6 | 4.69 | 2.72 |
| Ebstein's Malformation | 17 | 1 | 5.88 | 0.36 |
| Truncus Arteriosus | 58 | 10 | 17.24 | 1.23 |
| Origin of Left or Right Pulmonary Artery from Aorta | 4 | 1 | 25.00 | 0.08 |
| Aortopulmonary Window | 7 | 0 | 0.00 | 0.15 |
| Coronary Fistula | 7 | 1 | 14.29 | 0.15 |
| Anomalous Origin of Left Coronary from Pulmonary Artery | 22 | 0 | 0.00 | 0.47 |
| Aortic Stenosis - Valvular | 82 | 4 | 4.88 | 1.74 |

*Appendix 1 (continued): All pediatric congenital cardiac diagnoses in New York State, 1997-1999.*

| Diagnosis | # of Cases | # of Deaths | Crude Mort. Rate | % of All Cases |
|---|---|---|---|---|
| Aortic Stenosis - Discrete Subvalvular, Localized | 84 | 2 | 2.38 | 1.78 |
| Aortic Stenosis - Discrete Subvalvular, Tunnel Type | 16 | 0 | 0.00 | 0.34 |
| Aortic Stenosis - Supravalvular | 20 | 0 | 0.00 | 0.42 |
| Coarctation of Aorta | 198 | 1 | 0.51 | 4.20 |
| Coarctation of Aorta with Ventricular Septal Defect | 51 | 4 | 7.84 | 1.08 |
| Coarctation of Aorta with Other Cardiac Defect | 67 | 2 | 2.99 | 1.42 |
| Interrupted Aortic Arch | 37 | 7 | 18.92 | 0.79 |
| Vascular Rings and Slings | 43 | 0 | 0.00 | 0.91 |
| Hypoplastic Left Heart or Aortic Atresia | 206 | 49 | 23.79 | 4.37 |
| Congenital Mitral Valve Disease | 62 | 2 | 3.23 | 1.32 |
| Simple Transposition of Great Arteries (TGA) | 109 | 10 | 9.17 | 2.31 |
| TGA and Ventricular Septal Defect | 61 | 7 | 11.48 | 1.30 |
| TGA, Ventricular Septal Defect, and Pulmonary Stenosis | 52 | 4 | 7.69 | 1.10 |
| Other TGA | 124 | 11 | 8.87 | 2.63 |
| Double Outlet Right Ventricle (DORV) | | | | |
| With Subaortic Ventricular Septal Defect | 38 | 2 | 5.26 | 0.81 |
| With Subpulmonary Ventricular Septal Defect | 18 | 1 | 5.56 | 0.38 |
| Other DORV | 89 | 14 | 15.73 | 1.89 |
| Congenitally Corrected Transposition of the Great Arteries | 8 | 0 | 0.00 | 0.17 |
| Single Ventricle | 143 | 7 | 4.90 | 3.04 |
| Other Anomalies of Atrial Sinus | 4 | 0 | 0.00 | 0.08 |
| Other Congenital Heart Defect, including all cases with abnormal situs of the atria | 187 | 27 | 14.44 | 3.97 |
| **Statewide Total** | **4710** | **252** | **5.35** | **100.0** |

# APPENDIX 2

## Diagnosis Reference Group for 1997-1999 Pediatric Cardiac Surgery Analysis

The following table lists all diagnoses that are part of the reference group for the risk-adjusted analysis. These diagnosis codes are used as a comparison, when describing the significance of the diagnoses that are found in Appendix 3. To provide a better understanding of the reference group, included are the total number of cases, total number of deaths, and the observed mortality rate for each of the diagnoses.

**Appendix 2:** Diagnosis Reference Group for 1997-1999 Pediatric Cardiac Surgery Analysis

| Diagnosis | Total Cases | Total Deaths | Observed Mortality Rate |
|---|---|---|---|
| Patent Ductus Arteriosus and Weight >1500 g | 245 | 4 | 1.63 |
| Atrial Septal Defect, Secundum | 549 | 2 | 0.36 |
| Atrial Septal Defect, Primum | 29 | 0 | 0.00 |
| Sinus Venosus Defect | 47 | 0 | 0.00 |
| Other Partial Anomalous Pulmonary Connection (PAPVC) | 20 | 0 | 0.00 |
| Atrial Septal Defect and PAPVC | 43 | 0 | 0.00 |
| Cor Triatrialum | 4 | 0 | 0.00 |
| Paramembranous Ventricular Septal Defect | 409 | 3 | 0.73 |
| Subpulmonary Ventricular Septal Defect | 30 | 0 | 0.00 |
| Other Single Ventricular Septal Defect | 100 | 2 | 2.00 |
| Ventricular Septal Defect and Aortic Incompetence | 39 | 0 | 0.00 |
| Aneurysm of Sinus of Valsalva | 3 | 0 | 0.00 |
| Aortic-Ventricular Tunnel | 1 | 0 | 0.00 |
| Pulmonary Valve Stenosis | 53 | 0 | 0.00 |
| Aortopulmonary Window | 7 | 0 | 0.00 |
| Anomalous Origin of Left Coronary from Pulmonary Artery | 22 | 0 | 0.00 |
| Aortic Stenosis - Discrete Subvalvular, Tunnel Type | 16 | 0 | 0.00 |
| Aortic Stenosis - Supravalvular | 20 | 0 | 0.00 |
| Coarctation of Aorta | 198 | 1 | 0.51 |
| Vascular Rings and Slings | 43 | 0 | 0.00 |
| Congenitally Corrected Transposition of the Great Arteries | 8 | 0 | 0.00 |
| Other Anomalies of Atrial Sinus | 4 | 0 | 0.00 |
| **Total for Reference Group** | **1890** | **12** | **0.63** |

# APPENDIX 3

## 1997-1999 Risk Factors for Pediatric Cardiac Surgery In-Hospital Mortality

The significant pre-procedural risk factors for in-hospital mortality following pediatric cardiac surgery in 1997-1999 are presented in the Appendix 3 table.

Roughly speaking, the odds ratio for a risk factor represents the number of times more likely a patient with that risk factor is of dying in the hospital during or after pediatric cardiac surgery than a patient without that risk factor, all other risk factors being the same. For example, the odds ratio for the risk factor "severe cyanosis" is 1.561. This means that a patient with severe cyanosis is approximately 1.561 times more likely to die in the hospital after undergoing cardiac surgery than a patient without severe cyanosis, all other conditions being the same.

Included in the risk profile of a patient is the diagnosis on admission to the hospital. This affects the risk of survival and is determined in relation to the reference group that is described in Appendix 2. For example, a patient admitted with the diagnosis of Hypoplastic Left Heart Syndrome has a 22.154 times greater chance of dying in the hospital during or after pediatric cardiac surgery than a patient having a diagnosis in the reference group (Appendix 2), all other risk factors being the same.

For all risk factors in Appendix 3 and diagnosis in the table there are only two possibilities – having the risk factor or not having it. For example a patient has severe cyanosis or does not; a patient has Hypoplastic Left Heart Syndrome or does not.

**Appendix 3**: Multivariable risk factor equation for pediatric congenital cardiac surgery in-hospital mortalities in New York State in 1997-1999.

| Patient Risk Factor | | LOGISTIC REGRESSION | | |
|---|---|---|---|---|
| | Prevalence (%) | Coefficient | P-Value | Odds Ratio |
| **Demographic** | | | | |
| Age <30 days | 17.62 | 1.1858 | < .0001 | 3.273 |
| Age 30 days to 1 year | 29.47 | 0.7788 | 0.0002 | 2.179 |
| Female Gender | 45.33 | 0.4206 | 0.0040 | 2.523 |
| **Comorbidities** | | | | |
| Arterial pH <7.25 | 0.91 | 1.2485 | 0.0011 | 3.485 |
| Pulmonary Hypertension | 13.21 | 0.5346 | 0.0028 | 1.707 |
| Severe Cyanosis | 16.58 | 0.4454 | 0.0072 | 1.561 |
| Significant Extracardiac Anomalies | 6.50 | 0.9446 | < .0001 | 2.572 |
| Ventilator Dependence, Pre-op | 10.98 | 0.6897 | 0.0002 | 1.993 |
| **Diagnosis** | | | | |
| Aortic Stenosis – Discrete Subvalvular, Localized | 1.78 | 1.9456 | 0.0128 | 6.998 |
| Aortic Stenosis – Valvular | 1.74 | 2.2758 | 0.0002 | 9.735 |
| Atrial Septal Defect (ASD) & Mitral Valve Anomaly | 1.08 | 2.1537 | 0.0062 | 8.616 |
| Coarctation of Aorta with Other Cardiac Defect | 1.42 | 0.6215 | 0.4335 | 1.862 |
| Coarctation of Aorta with Ventricular Septal Defect | 1.08 | 1.2340 | 0.0510 | 3.435 |
| Complete Atrioventricular Canal Defect | 5.39 | 1.5856 | 0.0002 | 4.882 |
| Congenital Mitral Valve Disease | 1.32 | 1.7942 | 0.0228 | 6.014 |

***Appendix 3*** *(continued): Multivariable risk factor equation for pediatric congenital cardiac surgery in-hospital mortalities in New York State in 1997-1999.*

| Patient Risk Factor | LOGISTIC REGRESSION | | | |
|---|---|---|---|---|
| | Prevalence (%) | Coefficient | P-Value | Odds Ratio |
| **Diagnosis** *(continued)* | | | | |
| Coronary Fistula | 0.15 | 3.5596 | 0.0028 | 35.149 |
| Double Outlet Right Ventricle w/ subaortic VSD | 0.81 | 1.8197 | 0.0241 | 6.170 |
| Double Outlet Right Ventricle w/ subpulmonary VSD | 0.38 | 1.9409 | 0.0742 | 6.965 |
| Ebstein's Malformation | 0.36 | 1.5921 | 0.1690 | 4.914 |
| Hypoplastic Left Heart or Aortic Atresia | 4.37 | 3.0980 | < .0001 | 22.154 |
| Interrupted Aortic Arch | 0.79 | 2.3962 | < .0001 | 10.981 |
| Multiple Ventricular Septal Defect (VSD) | 0.68 | 2.0591 | 0.0054 | 7.839 |
| Origin of Left or Right Pulmonary Artery from Aorta | 0.08 | 2.1403 | 0.1090 | 8.502 |
| Other Congenital Heart Defect, including Abnormal Situs of the Atria | 3.97 | 2.9602 | < .0001 | 19.302 |
| Other Double Outlet Right Ventricle | 1.89 | 2.9260 | < .0001 | 18.653 |
| Other Transposition of the Great Arteries | 2.63 | 2.0494 | < .0001 | 7.763 |
| Pulmonary Atresia with Intact Ventricular Septum | 2.04 | 1.7331 | 0.0007 | 5.658 |
| Simple Transposition of Great Arteries (TGA) | 2.31 | 1.6083 | 0.0007 | 4.994 |
| Single Ventricle | 3.04 | 1.7137 | 0.0007 | 5.549 |
| Tetrology of Fallot (TOF) | 8.22 | 1.3177 | 0.0028 | 3.735 |
| TGA with VSD | 1.30 | 2.1049 | < .0001 | 8.206 |
| TGA, VSD, and Pulmonary Stenosis | 1.10 | 2.2296 | 0.0006 | 9.296 |
| TOF with Absent Pulmonary Valve | 0.38 | 2.4794 | 0.0041 | 11.935 |
| TOF with Other Major Cardiac Defect | 1.36 | 1.6425 | 0.0160 | 5.168 |
| TOF with Pulmonary Atresia | 3.80 | 2.0862 | < .0001 | 8.054 |
| Total Anomalous Pulmonary Venous Connection | 2.21 | 2.1000 | < .0001 | 8.166 |
| Tricuspid Atresia | 2.72 | 1.6871 | 0.0014 | 5.404 |
| Truncus Arteriosus | 1.23 | 2.7102 | < .0001 | 15.032 |
| VSD w/ Straddling or Overriding Tricuspid Valve | 0.23 | 3.1503 | 0.0006 | 23.342 |

Intercept - 5.9707

C Statistic - 0.855

# NYS PEDIATRIC CARDIAC SURGERY CENTERS

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

** Bellevue Hospital Center
First Avenue and 27 th Street
New York, New York 10016

** 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 210 th 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

*** North Shore University Hospital
300 Community Drive
Manhasset, New York 11030

*** St. Francis Hospital
Port Washington Boulevard
Rosyln, New York 11576

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 of Brooklyn
450 Lenox Avenue
Brooklyn, New York 11203

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

* As of 2000 this program is no longer active.
** These programs closed in 2000 and reopened in 2003
*** These programs are currently not active.

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