

The Congenital Heart Surgeons' Society (CHSS) is a group of 70 pediatric heart surgeons who meet once a year to discuss problems of mutual interest in patient management. The history of the group goes back to the early days of cardiac surgery in the mid of 1950s, when 16 surgeons met annually to relate their early pioneering experience in operating on children with congenital heart defects.

In 1985 Dr. John Kirklin and Dr. Eugene Blackstone proposed that the centers pool their experience in managing infants with rare congenital anomalies of the heart. Because the prevalence of congenital heart disease is small, i.e. 8/1000 live births, and the occurrence of any one of the many possible congenital anomalies is quite rare, it seemed appropriate to combine experience from the institutions represented by the CHSS surgeons.

The initial data collection included information on babies in the first 2 weeks of life, born with complete transposition of the great arteries, and who were admitted to any one of the CHSS institutions. During the four years of the data collection, information on over 900 babies with transposition was collected.

Data collection required the establishment of a Data Center, initially in Birmingham, Alabama. The personnel in the Data Center collated the information, collected reports from the various institutions, and entered all of the information into computerized data files. They also conducted an annual review to follow the progress of the babies entered in the study. The era of data collection for these patients was an important one because the surgical management of the neonates with transposition changed dramatically from an atrial or inflow redirection to an outflow or arterial operation. The former was not performed until age of 3 to 18 months, whereas the arterial switch operation was performed routinely in the first two weeks of life. The data analysis on these patients has resulted wealth of information in 7 publications to date.

The success of data collection in the transposition babies led to 6 subsequent studies of infant groups including pulmonary atresia intact septum, pulmonary stenosis, interrupted aortic arch, coarctation, critical aortic stenosis, and aortic atresia and most recently tricuspid atresia.

In 1997, the Data Center moved from Birmingham, Alabama to the Hospital for Sick Children in Toronto. The Data Center employs 3.5 full-time people and has two physicians/surgeon-consultants. Funding is provided by the institutions of the surgeon members, and substantial support by the Hospital for Sick Children.