Inova Children's Hospital Cardiac Outcomes Report 2018

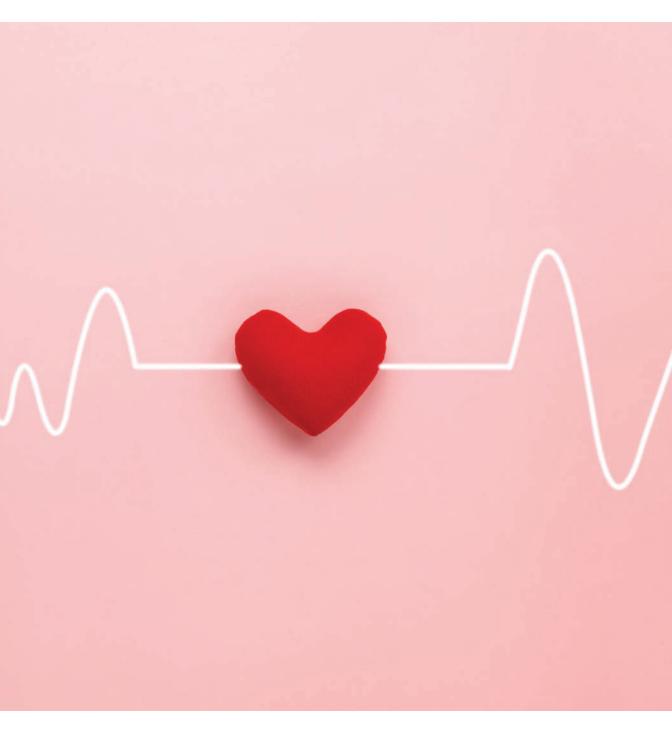






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A Year of Progress and Expansion

We are pleased to present the 2018 Inova Children's Hospital Cardiac Outcomes Report, based on 2017 data, which showcases the continued growth and development of our nationally recognized program.

Inova Children's Heart Center is one of the largest and most successful in the mid-Atlantic region. Based at the new, state-of-the-art Inova Children's Hospital and outpatient cardiology clinics throughout Northern Virginia and Maryland, we provide specialized care to children of all ages.

Every year, our cardiac surgeons perform over 250 cardiac surgeries. In addition, our multidisciplinary team of experienced cardiologists, surgeons, intensivists, anesthesiologists, nurse practitioners and nurses provide care to patients ranging from fragile newborns facing complex, challenging health problems, to adults with complex congenital heart disease.

Our 2018 outcomes report reflects these efforts. It demonstrates the many ways in which we provide consistently high performance in outcomes, access, value and experience for children with cardiac diseases and their families.

Some of the year's highlights include:

- A significant increase in cardiac surgical procedures
- Advancements in our fetal heart program
- Creation of a dedicated electrophysiology program
- Ongoing growth of our Adult Congenital Heart Disease Program in partnership with Inova Heart and Vascular Institute
- Creation of dedicated pediatric cardiac genomics program

As part of Inova Health System, we offer families seamless access to the full range of therapies and the latest technologies. One of the most exciting is genomics and personalized medicine, which can identify hereditary conditions in young children and provide insights into the most appropriate early treatments.

Our goal is to achieve the best possible outcome for every patient and provide long-term support for every family. Thank you for helping us advance exceptional heart care in our community and provide groundbreaking, lifesaving services to children throughout our region.

Nitchell Cohen, MD, FACC, FHRS Co-Director, Pediatric Heart Program Chief, Pediatric Cardiology

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Lucas Collazo, MD Co-Director, Pediatric Heart Program Chief, Cardiac Surgery

Cardiac Surgery

Our cardiac surgery program provides patients with a continuum of care that spans a lifetime. We perform a wide spectrum of surgeries for congenital heart defects in neonates, infants, children, teenagers and adults. Our goal is to deliver innovative surgical care in a compassionate, family-centric environment.

Multidisciplinary collaboration ensures the best care possible for every patient.

- Our surgical team includes two full-time pediatric cardiac surgeons experienced in all aspects of pediatric and congenital cardiac surgery, dedicated physician assistants, nurse first assistants, anesthesiologists, nurse anesthetists, perfusionists and operating room nurses.
- Following surgery, cardiac-focused intensivists and nurse practitioners care for patients in the Pediatric Cardiovascular Intensive Care Unit.
- As patients progress toward discharge, the surgical team, cardiologists, case managers, occupational, speech and physical therapists, Child Life specialists, and a dietician coordinate and guide care.

We participate in the Society of Thoracic Surgeons Congenital Heart Surgery national database (STS) to ensure the highest quality care with results comparable to the country's leading pediatric heart centers. The ability to benchmark our performance is a powerful tool that drives our improvement efforts.

In 2017, Inova Children's Heart Center performed 232 cardiac surgical procedures,

| Surgical Volume | |
|---------------------------------|------|
| Pediatric cardiac cases | 201* |
| Adult congenital surgical cases | 31 |
| Total | 232 |

*Total pediatric cardiac cases include 43 neonatal cases.

Neonatal Patients

| Complex cardiac repairs | 24 |
|----------------------------------|----|
| PDA ligations - premature infant | 19 |
| Total | 43 |

| Pediatric Congenital Heart Surgery | | |
|------------------------------------|-----|--|
| ASD | 6 | |
| VSD | 17 | |
| TOF | 11 | |
| ASO | 5 | |
| AVC (complete, partial) | 6 | |
| PAPVR | 1 | |
| TAPVR | 1 | |
| COA/hypoarch | 10 | |
| Glenn/Fontan | 9 | |
| Systemic Pulm shunt | 5 | |
| Pacer/ICD | 8 | |
| PVR/RVOT procedures | 11 | |
| AVR/supra and sub valvar | 5 | |
| MV repair/replace | 5 | |
| ECMO cannulation | 11 | |
| ECMO procedures | 12 | |
| PDA ligation | 21 | |
| Thoracic | 6 | |
| Other STAT category | 10 | |
| Other cardiac non-pump | 41 | |
| Total | 201 | |

a significant increase over previous years. Ambulatory Cardiology

Our ambulatory cardiology program expands our reach and makes it easier for patients to receive the care they need close to home.

- Our cardiologists practice in ambulatory settings throughout Maryland and Virginia, and our team cares for infants in nurseries and neonatal intensive care units across the region.
- Expanded telemedicine capabilities improve access for patients who live in remote areas. Cardiologists can review clinical information, such as electrocardiograms, echocardiograms and remote rhythm monitors so as to develop a care plan that is not only contemporary but convenient.
- Our electrophysiology program offers convenient home-based monitoring of patients with pacemakers, minimizing travel and missed work and school days.
- Many of our clinics offer exercise stress tests, as well as Holter monitoring and implantable loop recorders for evaluation of arrhythmias.

As our ambulatory program grows, we use the American College of Cardiology's Adult Congenital and Pediatric Cardiology Quality Metrics for chest pain, Kawasaki disease. infection prevention. and more.

Outpatient visits: 16,298

Cardiac Imaging

Inova Children's Heart Center offers state-of-the-art cardiac imaging to diagnose the unique medical and surgical needs of newborns, children and adults in a safe, family-friendly environment.

Our advanced procedures include:

- Fetal echocardiography to detect heart problems before birth, allowing for earlier medical or surgical intervention once the baby is born.
- Transesophageal echocardiography (heart scan with endoscopy) to guide and facilitate surgical and catheter-based procedures, and 3D and intracardiacechocardiography for better visualization of the heart chambers and valves.

Our team of experienced, certified pediatric sonographers work in tandem with cardiologists to produce comprehensive, high-quality pictures of the heart. We monitor program quality by reviewing the correlation between pre-operative imaging and surgical findings. Our echocardiography lab is accredited by the Intersocietal Accreditation Commission (formerly ICAEL).

Transthoracic ECHOCARDIOGRAMS: 10,388

Advanced Multimodality Imaging

Inova Children's Heart Center offers state of the art imaging technology including both cardiac MRI and CT imaging. The Inova Fairfax MRI center was the first location in the United States to offer comprehensive cardiac MRI with 4D Flow imaging, a novel technique to evaluate three dimensional flow dynamics in the entire heart and surrounding vasculature. This technique allows for decreased scan time without breath holding and may reduce the need for anesthesia in younger children.

Inova Fairfax Medical Campus recently added a new

GE Revolution CT scanner. This will allow for lower dose imaging techniques for our pediatric patients, as well as whole heart imaging in a single beat. Although MR is our imaging technique of choice in congenital heart disease, CT is a valuable tool in certain conditions. The new low dose scanner will afford us the ability to obtain these specialized images with a low dose of radiation and without the use of anesthesia.

Pediatric cardiac studies are performed and interpreted by fellowship trained cardiac imagers and presented at our weekly multidisciplinary conference to allow a comprehensive review of the imaging.

Interventional Cardiology

Inova Children's Heart Center offers a wide array of diagnostic and interventional procedures in specially designed and equipped pediatric cardiac catheterization labs. We use catheters, balloons and coils designed uniquely for children and infants to open blocked valves, dilate narrowed vessels, and close holes or abnormal connections in the heart.

Catheter-directed therapies include:

- Closing a patent ductus arteriosus
- Closing an atrial or ventricular septal defect
- Dilating an aortic or pulmonary valve
- Dilating a coarctation of the aorta
- Transcatheter pulmonary valve replacement (Melody[™] and Edwards[™] valves)
- Coiling abnormal vessels in the heart or lungs
- Balloon atrial septostomy
- Diagnostic cardiac catheterization

In addition, we installed state-of-the-art Phillips imaging equipment, which delivers the clearest pictures with the lowest radiation dose possible.

To ensure that we provide high-quality care and outcomes, we participate in the IMPACT database.

a) b) b) 14 year-old patient with abnormal MRI

14 year-old patient with abnormal MRI demonstrating a dilated left main coronary artery. 3D images demonstrating a dilated left main coronary artery with a tortuous fistulous connection to the right ventricular outflow tract just proximal to the pulmonic valve. Key: blue-right ventricular outflow tract and pulmonary arteries. 3D images: a) RAO; b) slight LAO





Electrophysiology Program

The Inova Children's Heart Center electrophysiology program offers a full complement of diagnostic and treatment options for children with known or suspected heart rhythm problems. As the largest outpatient program in Northern Virginia, we perform more than 15,000 electrocardiograms and administer 1,000 ambulatory monitors annually.



Comprehensive services include:

- Mitchell Cohen, MD, FACC, FHRS
- *Fetal arrhythmia monitoring.* Our electrophysiology clinicians work with Inova's obstetricians, maternal-fetal medicine specialists, cardiologists, and neonatologists to monitor fetuses with suspected arrhythmias. In collaboration with Inova Heart and Vascular Institute's genomics clinic, we can now detect hereditary arrhythmias, such as Long QT syndrome, in utero and provide timely treatment.
- Pacemakers/defibrillators. We monitor patients with pacemakers and defibrillators via in-office checks and convenient home-based monitoring. Transvenous pacemakers and defibrillators are implanted in our new cardiac catheterization lab and children recover overnight in our cardiac intensive care step-down unit.
- Ablation. We use the latest technology, including radiofrequency energy, cryoablation and irrigated radiofrequency, to treat supraventricular and ventricular arrhythmias. All ablations are performed in our newly renovated biplane electrophysiology lab. 3D mapping helps us locate arrhythmias with minimal fluoroscopy exposure. In addition, advanced automation, impedance field flexibility, and magnetic field precision significantly shorten procedure time. In 2017, we had a 95% success rate for children with WPW and all forms of supraventricular arrhythmias. Many children who previously required anti-arrhythmic medication and had activity restrictions can now safely participate in unrestricted activities without any medication.
- Genetic Heart Disease. Inova Children's Heart Center is in a unique position to evaluate and treat families with genetic heart disease. Our multidisciplinary team of adult and pediatric cardiologists and dedicated pediatric genetic counselors currently follows children, parents, siblings and extended family with inherited life-threatening and rare arrhythmias as well as cardiomyopathies. We work with researchers at Inova Translational Medicine Institute to identify and tailor the best treatment options for these patients and their entire family. This joint program between the pediatric and adult heart centers at Inova provides care across generations of families.
- Sudden Cardiac Death Prevention Program. We promote community awareness to identify children at risk of sudden life-threatening events. In April 2018, we hosted our first symposium to educate pediatricians, family practitioners and other providers on risk factors and early warning signs for sudden cardiac death. In addition, we are working to establish mandatory CPR training for all high school students in Northern Virginia.

EP Procedures, Q3 -Q4 2017

| Total EP Procedures (< 21 years of age) | | | |
|---|----|--|--|
| Total Procedures | 39 | | |
| | 29 | | |

Mitchell Cohen, MD, FACC, FHRS Co-Director, Pediatric Heart Program Chief, Pediatric Cardiology



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Adult Congenital Heart Program

Because of the success of pediatric cardiac care teams over the past decades, we now have a population of adults who previously may not have survived childhood. Established in 1994, Inova's Adult Congenital Heart Program was one of the first programs in the country to care for patients with congenital heart disease. Today, it offers complete continuity of care for adults with a variety of congenital heart defects, including those complicated by heart rhythm problems, heart failure and pulmonary hypertension. For women with congenital heart defects, we partner with our colleagues in obstetrics to achieve the safest delivery plans possible for mother and baby.

A multidisciplinary team of board-certified specialists from Inova Heart and Vascular Institute and Inova Children's Heart Center collaborate to provide highquality care for congenital heart disease at all stages. Patients have the advantage of seamless access to the collective expertise of Inova's highly skilled pediatric and adult specialists in a single location, to improve outcomes and enhance quality of life. Areas of specialization include:

- Adult Congenital Cardiac Catheterization. Cardiac surgeons and interventional cardiologists perform advanced procedures such as the minimally invasive transcatheter aortic valve replacement (TAVR) and catheter-based pulmonary valve replacement.
- Adult Congenital Electrophysiology. Electrophysiologists with specialized expertise in management of adults with cogenital heart disease treat all types of arrhythmias, including the most challenging heart rhythm disorders once considered untreatable. Our Atrial Fibrillation Program features the Maze surgical procedure and rigorous patient follow-up. We also place biventricular pacemakers to resynchronize the heart and improve myocardial dysfunction.
- Advanced Cardiac Therapies. Inova's end-stage heart failure program offers mechanical cardiac assist programs, including the only Joint Commissioncertified ventricular assist device (VAD) program, as well as heart and lung transplantation. The Inova Pulmonary Hypertension Program was one of the first in the country accredited as a Comprehensive Care Center by the Pulmonary Hypertension Association to care for adults with congenital heart disease and pulmonary hypertension.
- Maternal-Fetal Medicine. Inova's high-risk obstetric specialists carefully
 manage women with congenital heart disease during pregnancy. The team
 also cares for women carrying a baby with suspected congenital heart
 disease that may require specialized pediatric care after birth. This includes
 specialized care for mother and baby during labor and delivery and
 post-natal care of the newborn.

| Adult Congenital Heart Surgery | 2017 |
|--------------------------------|------|
| ASD | 2 |
| AVR | 5 |
| MVR | 0 |
| PVR | 6 |
| PAPVR | 5 |
| Other (see below) | 13 |
| Total | 31 |

Other surgery types include partial AV canal, anomalous coronary artery, tricuspid valve surgery, pacemaker/ defibrillator, pectus surgery (thoracic)

Intensive Care

Inova Children's Hospital offers a full range of pediatric cardiac critical care services including critical care for children with heart disease all housed in a family-centered, comprehensive care environment. The critical care service is staffed 24/7 with board certified pediatric intensivists – clinicians who are trained in the most modern therapeutic modalities to care for critically ill children. The Intensive Care Unit (ICU) team is comprised of physicians, nurses, advanced practitioners, pharmacists, respiratory therapists, occupational and physical therapists who are expertly trained in the care of children who require this advanced level of care. Together, the team cares for more than 1,200 critically ill children each year.

Besides general ICU care, Inova Children's Hospital also offers specialty care for children with heart disease. The Pediatric Cardiac Intensive Care Unit (PCICU) is comprised of 8 beds devoted to the care of critically ill children with heart disease of all kinds, ranging from recovery post-surgery, to complex arrhythmias, to congestive heart failure. This specialty unit is staffed by critical care physicians, cardiologists, cardiovascular surgeons, physician assistants, nurse practitioners and nurses, all with additional training and expertise in the care of critically ill children with heart disease. The scope of care in the PCICU includes:

- The care of children before and after surgical repair of complex congenital cardiac defects
- Extra-corporeal membrane oxygenation (ECMO) support
- Heart failure management
- Arrhythmia management
- High-frequency oscillation ventilation
- Continuous renal replacement therapy
- Comprehensive hemodynamic monitoring

Our new, modern Pediatric Intensive Care Unit (PICU) is bright and beautiful. Our staff are highly trained experts in their fields. However, the real strength of Inova Children's Hospital PICU and PCICU lies in the commitment of our clinicians to our patients and their families. We are always striving for the highest quality care and the best possible outcomes by using a multi-disciplinary team approach that stresses open and effective communication among all team members, patients and family members.

Inova Children's Hospital Fetal Care Center

Inova Children's Hospital Fetal Care Center provides prenatal consultation and pediatric care planning for pregnant women suspected or at risk of carrying a fetus with a congenital heart defect.



L to R: Melissa Eatherly, FNP-BC, Margot Ahronovich, MD, Sharon Karr, MD and Erin Caulfield, BSN. To refer a patient to our Fetal Care program, please call 703.776.6371.

The center offers every resource expectant families could need, including expert evaluation and diagnosis, a coordinated delivery plan, and care for newborns after birth. In addition, expecting mothers can deliver their babies on-site at Inova Women's Hospital, providing continuity of care by the same fetal heart care team that cared for the baby in utero. This also ensures that mother and baby remain in the same facility after delivery. Our patients benefit from the combined expertise of pediatric cardiologists, cardiac surgeons, cardiac anesthesiologists, nurses, and a genetic counselor working hand-in-hand with maternal-fetal medicine specialists, obstetricians and others to provide comprehensive care. **Each year**, **our experienced fetal cardiac sonographers perform more than 1,000 fetal echocardiograms.**

Continuity of care sets our program apart. One call to our team including a nurse practitioner and patient navigator provides access to diagnosis, neonatal care and pediatric subspecialty care, along with the emotional, educational and logistical support services families need during this critical time.

Fetal ECHOCARDIOGRAMS: 1,028

Single Ventricle Interstage Program

The Single Ventricle Interstage Program provides comprehensive care and support for families of infants with complex conditions such as hypoplastic left heart syndrome and shunt-dependent circulation that requires intervention in stages. The Single Ventricle Interstage Program bridges the gap between the child's first and second heart procedures.

Our multidisciplinary team includes two cardiologists, physician assistants, a nurse navigator, clinic nurse, speech therapist and dietician. Because clear communication and care transition from hospital to home improves outcomes and survival, families receive extensive education to help them care for their child upon discharge, as well as home monitoring equipment to track their baby's vital signs and progress.

Patients are seen at regular intervals in our Single Ventricle Clinic along with follow-up with their primary cardiologist. In addition, our clinical nurse navigator checks in with parents every week by phone. Between appointments, parents have access to a dedicated phone line, where a clinical staff member is available to coordinate care, troubleshoot problems and discuss concerns.

To provide the highest quality care, we are part of the National Pediatric Cardiology Quality Collaborative.

Neurodevelopmental Clinic

Children with complex congenital cardiac disease are at increased risk for neurodevelopmental delays and disabilities. In 2012, the American Heart Association identified those infants at highest risk and recommended early screening and intervention in order to provide these children with the necessary resources to help them achieve their highest neurodevelopmental potential.

Inova Children's Heart Center partners with our pediatric rehabilitation specialists to provide this service to our "at risk" population. The Follow-Along Clinic provides developmental evaluation for infants and children who have experienced:

- Regional cerebral perfusion techniques, utilized for certain complex neonatal surgical procedures
- Extra-corporeal membrane oxygenation (ECMO) support
- Cardiac arrest event

The Pediatric Rehabilitation specialists consist of physical, occupational, speech and language therapists who utilize a standardized developmental assessment tool to determine:

- Mental abilities
- Motor skills
- Speech skills
- Problems of weakness or tone (via neurologic screening)

Recommendations are provided for:

- Home activities to promote infants' developmental potential
- Referral to community-based resource centers as appropriate

The Follow-Along Clinic team works with the patient, family and primary medical team to ensure that patients receive support in managing any neurodevelopmental concerns, even after they leave the hospital.

Pediatric Cardiac Anesthesia

Patients with congenital heart disease at Inova Children's Hospital are cared for by a dedicated team of pediatric cardiac anesthesiologists who understand their unique physiology and needs. Our team of board-certified pediatric anesthesiologists and experienced CRNAs provide comprehensive anesthesia care for patients anywhere that anesthesia or sedation is required. This includes:

- Cardiac operating room
- Catheterization lab
- NICU
- Radiology and MRI
- Pediatric sedation
- General operating rooms

Patients with congenital heart disease often require sedation and anesthesia for multiple procedures and our anesthesiologists work in collaboration with the entire cardiac team to ensure the safest outcomes.

Child Life Services



At Inova Children's Hospital, we believe that meeting the psychosocial needs of children and their families is an essential component of exceptional comprehensive care. Our certified Child Life specialists partner with physicians, nurses and the entire team to craft an experience that is not only comfortable and soothing, but also promotes healthy coping and healing strategies.

For children scheduled for cardiac surgery, the Child Life team provides:

- A pre-op tour that includes a developmentally appropriate description of what to expect
- Support during pre-op bloodwork, echocardiograms and other tests, as needed
- Hands-on preparation and support through admission and each step
 of the surgical process

In addition, Child Life Specialists also support children who come to the hospital for outpatient cardiac procedures.

Every year, the Pediatric Heart Program and Child Life Services hold a cardiac picnic for patients, their families and staff. This event helps to foster a sense of community within the pediatric cardiac program and allows time for patients and staff to reconnect - forging life-long relationships between our staff and the families they are so privileged to serve.

Nursing

The 8-bed Pediatric Cardiac Intensive Care Unit (PCICU) is housed within the larger, 26 bed state-of-the-art Pediatric Intensive Care Unit. Both can found within Inova Children's Hospital – a 226 bed pediatric quaternary care center.

The PCICU provides the highest level of care for a culturally diverse population of young patients and their families and serves as a referral unit within the pediatric hospital. The unit's scope of service ranges from birth to 21 years of age, with the majority of patients less than five years in age. Admission diagnoses consist of postoperative cardiac surgery, extra corporeal membrane oxygenation (ECMO), high-frequency oscillation ventilation, continuous renal replacement therapy, vasoactive drip management, as well as management of other life-threatening conditions including heart failure and arrhythmias.

The strength of the PCICU is its commitment to a team approach with joint accountability among staff, leadership, and the key stakeholders. Effective communication is critical to providing high quality care and outcomes for patients in a family-centered environment. The unit employs a systematic process to determine daily staffing needs, including the required skills and competencies to care for cardiac patients. Continuing education is provided to the cardiac nursing team; staff are assigned to patients within their experience and expertise, with advanced support nurses caring for the most complicated cases.

The PCICU has a strong commitment to reducing hospital acquired infections, and has participated in Solutions for Patient Safety (SPS) since 2014. Since 2014, Inova Children's Hospital has had on an ongoing commitment to hardwire CLABSI bundle compliance and to proactively address CLABSI events. Our active and comprehensive plan continues to evolve with dynamic team engagement. Inova Children's Hospital CLABSI rate is within the top 10% of the SPS network.

International Outreach



Our team at Inova Children's Hospital is dedicated to international outreach. The Pediatric Heart Program has provided cardiac care to children in need across the globe and led medical missions to Ecuador, Iran, Libya, Macedonia and Haiti.

Marcelo Cardarelli, MD and young patient in Ecuador.

Research

Inova Children's Hospital is actively involved with clinical research along a spectrum of fetal cardiology, congenital heart disease, ACHD, and complex hereditary arrhythmias. Inova has also been supported by two generous external grants to provide CME sponsored lecturers throughout the year by visiting professors. The Pediatric Heart Program at Inova participates in multi-institutional research. Inova has an active collaboration with the Inova Translational Medicine Institute (ITMI), which affords clinicians a unique opportunity to study whole genome sequencing to decode the genetic and genomic factors that contribute to causing congenital anomalies. Our heart program is currently involved in research to improve our understanding of the functional genomic abnormalities associated with hereditary arrhythmias such as long QT syndrome, CPVT, ARVD, and Brugada Syndrome. Cardiac conditions in children are unique and show variable degrees of expressivity even within families. By partnering with ITMI, we are committed to better understanding these unique genetic and genomic factors within families and applying these innovative discoveries for the application of innovative personalized health.



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Single Ventricle Care Team

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Giving to Inova

Inova, a not-for-profit system, is a global leader in personalized health, which leverages precision medicine to predict, prevent and treat disease, enabling individuals to live longer and healthier lives. Inova's five hospitals serve more than two million people each year from throughout the Northern Virginia and the Washington, DC metro area. Inova is home to the nationally recognized Inova Children's Hospital, with a Level IV neonatal intensive care unit, 226 beds and experts from 40 pediatric subspecialties, including one of the area's largest heart programs with pediatric cardiology and cardiac surgery.

Inova relies on community support to provide world class care close to home. If you would to support the Pediatric Cardiac Program at Inova Children's Hospital, please contact Kirstin McArthur, Director of Leadership Giving, at 703.776.6081 or kirstin.mcarthur@inova.org.





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