

Children's National Heart Institute

Measuring the Quality of Our Program By the Quality of Their Lives



Children's National
Medical Center

Children's National
HeartInstitute





Camdyn with his parents,
Erin and Bryan, May 2011

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One Family's Story

Through The Parent's Letter Project, parents of patients at Children's National provide support to families undergoing similar treatments by writing letters of advice and support.

Dear parent of a baby with a heart defect,

In June of 2009, my husband and I found out we were expecting. I remember the technician spending a long time looking at his heart. Initially I figured it was just because the heart was intricate and needed a little more attention, but it wasn't long before I knew that was just wishful thinking. The doctor came into the room and explained to us that he thought our baby had something called an Aortic Truncus. He referred us to Children's National Medical Center for a fetal echocardiogram.

The days before our Children's National appointment were depressing and difficult to say the least. My husband and I spent our first anniversary in the perinatologist's office discussing amnios and genetic testing. By the time we got to Children's we were just ready to confirm our diagnosis. We hoped for the best but prepared for the worst.

That was the day we met Mary Donofrio, MD. She came into the exam room and introduced herself. She spent some time with the echo tech imaging the baby's heart and afterwards asked us to meet with her in the conference room. She had such a positive attitude, she put me at ease.

In the conference room she explained that our son had something called Tetralogy of Fallot. She drew us pictures of the heart and its defects, explained that he would need surgery and answered all of our questions thoroughly. I felt scared and relieved at the same time. I was happy to have a diagnosis, but sad that our unborn child would have to undergo open heart surgery.

Our beautiful son, Camdyn, was born March 2, 2010. We had three wonderful months at home with Camdyn. I enjoyed every second with him and tried not to dwell on his upcoming surgery. The day before surgery we went in for his pre-op day. Camdyn's oxygen saturation had dropped from the low 90s to 64 percent. They decided us to keep us

overnight. The staff on the Heart and Kidney Unit were so attentive and kind. They made us feel completely comfortable and safe. Thanks to them, we were actually able to get some sleep that night.

The next morning we walked Camdyn down to the operating room. We were met by the team in the hallway. I remember there being several warm faces all waiting there for our baby. All these people were responsible for the well-being and outcome of our precious baby boy and I didn't hesitate for a second. I felt completely confident in every single person standing there.

Camdyn spent two days in the Cardiac ICU and then three days in the Heart and Kidney Unit (HKU). He had no post-operative complications and a very uneventful hospitalization. It was amazing to see him intubated the first day with lines and tubes everywhere and then by the last day he was cooing, smiling, and acting like his old self (just pinker)! It was truly miraculous.

The nurses, techs, and doctors at Children's National were absolutely amazing. They were always professional, compassionate, and kind. Each person touched us in ways that are unimaginable. There is no thanks that will ever be big enough. They gave our son the opportunity to live a normal, healthy, happy life.

Camdyn is turning one a week from today. He started walking at nine months and has a personality that you can't help but love. He is a beautiful child with an amazing story. We are so proud of him! He has changed our lives in countless ways. He's taught us to live every second to the fullest and that life is truly precious. He's given us direction and purpose and we thank God for him every single day.

Sincerely,
Camdyn's parents, Erin and Bryan



Welcome to the *Children's National Heart Institute*

Children's National Heart Institute at Children's National Medical Center has emerged as one of the top cardiac centers in the nation. The Institute brings together a multidisciplinary team to provide specialized expertise and supports all facets of congenital heart disease. Our team of dedicated cardiac surgeons, cardiologists, anesthesiologists, and cardiac intensivists care for children and adults with a wide range of congenital and acquired heart disease.

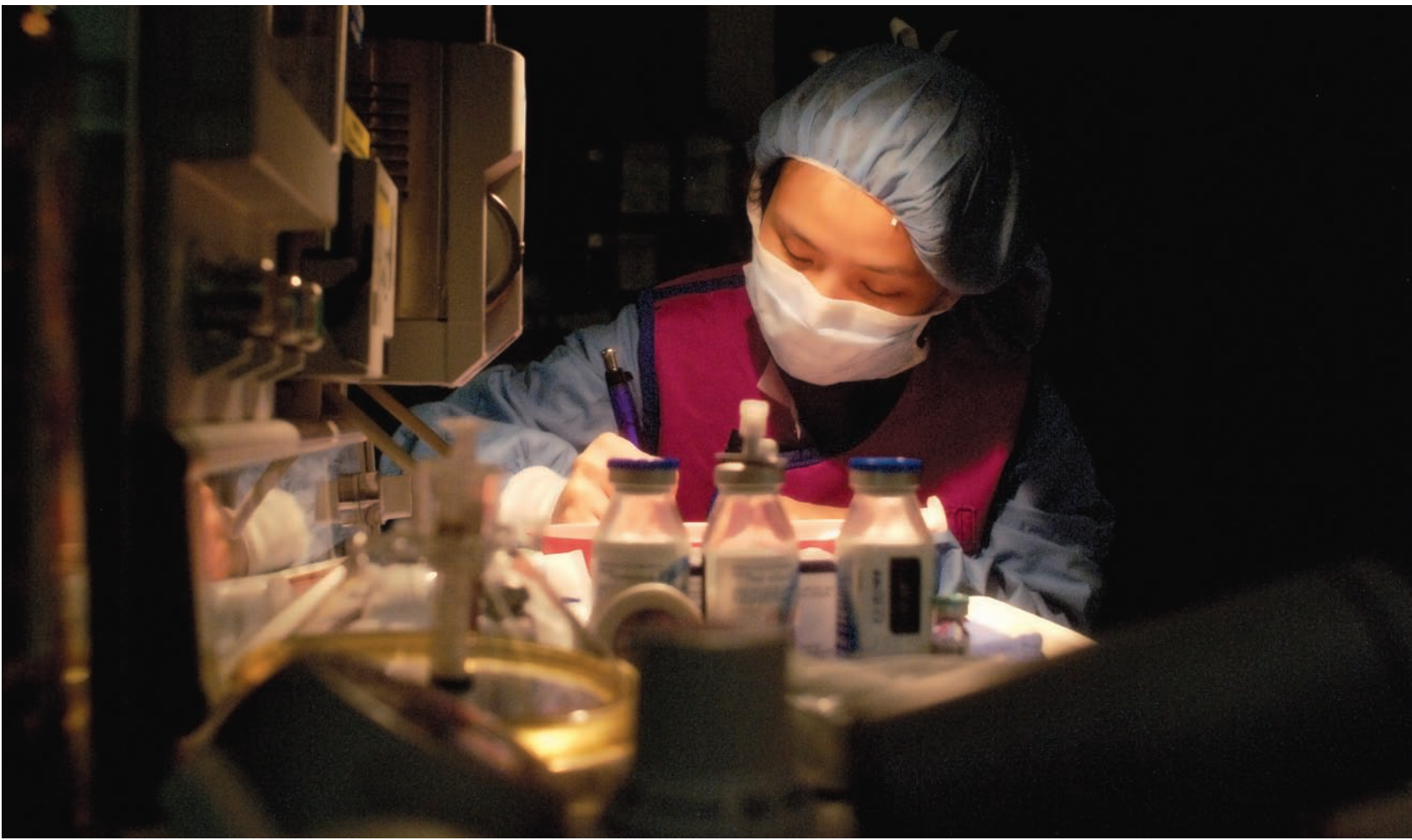
The Children's National Heart Institute team includes national and international leaders in pediatric cardiology, cardiac surgery, cardiac intensive care, and cardiac anesthesia. Additional expertise in cardiac imaging, cardiac rhythm disorder, interventional cardiology, and adult congenital heart disease ensure the best care across the total spectrum of cardiac disease. Specially trained nurses, nurse practitioners, genetic counselors, social workers, nutritionists, case managers, child life specialists, and pharmacists complement the core team.

Our work revolves around children, which provides us an intuitive understanding about how to treat them – and their families. A child's illness affects the entire family, which is why we focus our care from the perspective of the family. Our team members are specially trained in family-centered care. We provide families with the emotional and spiritual support needed to thrive before, during, and after their time at Children's National.



“Every nurse, technician, doctor, and administrator we dealt with has gone that extra mile to make sure the best prognosis was in reach.”

— Ian's mom and dad



Our Approach: *Excellence Through Teamwork*

Children's National Heart Institute offers a full range of cardiac subspecialties and diagnostic procedures to treat children with cardiac defects. Our goal is to provide early intervention to maximize the quality of our patients' lives, and ease the stress on their families. Children's National Heart Institute takes a multidisciplinary approach, bringing all the necessary experts to the family to provide world-class care to our patients.

Our patients come from all over the world to see our highly trained specialists. Whether it's a child inside the Beltway or half way around the world, Children's National Heart Institute provides world-class care in a family-centered environment throughout the healthcare

continuum. Children's National Heart Institute provides unparalleled expertise in four key areas: cardiology, cardiovascular surgery, intensive care and cardiac anesthesia.

Cardiology

FETAL HEART PROGRAM

Children's National Heart Institute's youngest patients are cared for through the **Division of Fetal and Transitional Medicine** and the **Fetal Heart Program**. Through this innovative program, the unborn child is cared for as a separate and individual patient. Comprehensive



“We did telemedicine with Children’s National – what a relief to have their experts review the echocardiogram in real time and provide possible answers.”

— Sammy’s parents

care begins *in utero* and is coordinated and in partnership with referring maternal fetal medicine specialists and obstetricians with many subspecialties, including cardiology, cardiac surgery, genetics, and radiology. Our elite medical team utilizes some of the most advanced techniques and equipment available. The goal is to understand how heart defects affect fetal well-being *in utero* and determine when and if intervention is needed. Once a diagnosis is made, parents are counseled so that they are prepared for what to expect for the duration of the pregnancy and after delivery. This unique program maximizes planning time and allows for early treatment of a variety of heart abnormalities – often within moments of delivery. A unique feature of the program is while our team cares for the fetal heart, we monitor brain function and other aspects of fetal development to ensure the best outcomes for parents.

ECHOCARDIOGRAPHY

Children’s National Heart Institute utilizes leading-edge technology to augment the care for our patients. Children’s pediatric **echocardiography** laboratory is one of the most advanced in the United States, performing more than 17,000 studies annually. State-of-the-art technology, including transesophageal, fetal, three-dimensional, intracardiac, stress, and digital echocardiography, is readily available. Our team includes international experts in the area of echocardiography, and houses the world’s first pediatric digital echocardiography laboratory. Children’s echocardiography laboratory is connected via telemedicine to 17 area hospitals, allowing for instant diagnoses and treatment of infants with suspected heart disease throughout the region.

Children’s National also uses cutting-edge, specialized echocardiography for our patients. **Transesophageal echocardiography**, a specialized form of echo in which the transducer is placed in the esophagus, allows for better images in bigger patients, including adults, and enables our team to monitor the heart during heart surgery. **Intracardiac echocardiography**, a form of echo, places a tiny echo probe on the end of a catheter. This catheter is put in the heart, giving the team pictures of the heart from the inside. Intracardiac echos are primarily used in our Cardiac Catheterization Lab.

CARDIAC MRI

Children’s National Heart Institute is one of only a few pediatric programs to have a **Cardiac MRI** program run jointly by pediatric cardiology and pediatric radiology. By working together these physicians are able to capture anatomic and physiologic details that were previously unattainable.

The study is performed without radiation exposure, and can yield high resolution images of the moving heart and vascular structures that are not limited by body size or other anatomic constraints. In addition to improved visualization of complex anatomy, cardiac MRI also can be used to accurately measure hemodynamic parameters such as heart size and function, cardiac output, blood flow volumes, and pressure gradients. Cardiac MRI studies typically require 1-1.5 hours to perform, and young children or other individuals who have difficulty remaining still may require sedation by a fellowship-trained pediatric anesthesiologist. The Division of Fetal and Transitional Medicine also offers MRI as part of an integrated approach to complete evaluation of the fetus with complex cardiac disease that may have additional congenital anomalies.

Children's National and the National Heart Lung and Blood Institute/ National Institutes of Health (NHLBI/NIH) aim to shape the future of diagnostic and image guided cardiac intervention for children and adults with congenital heart disease. In radiological sciences, Children's National is a premier program in applying state-of-the-art technology to the diagnosis and treatment of children. NHLBI/NIH has a long history of translating scientific and technical developments into clinical practice. This exciting Children's National and NHLBI/NIH collaboration to bring novel therapy to our nation's children builds on the joint mission to improve the nation's health by improving the standard of care for the pediatric patient.

ELECTROPHYSIOLOGY PROGRAM

Children's National Heart Institute provides **electrophysiology** testing for the management of arrhythmias and syncope. Children's staff includes the first pediatric electrophysiologist in the region to utilize cryoablation for children with cardiac rhythm abnormalities. The electrophysiology service utilizes a team approach of physicians, nurse practitioners, and technicians to provide state-of-the-art care to children and young adults with these conditions.

Children's National offers not only the standard treatment of radio-frequency ablation as a means to cure arrhythmias, but now offers **cryoablation technology**. Some arrhythmias originate in high-risk locations of the heart, where radio-frequency may damage normal heart tissue and result in the need for a pacemaker. Previously, it was safer for the patient to remain on a lifetime of medications rather than correct the problem. Now, we can use cryoablation, which cools the tissue in stages, allowing doctors to pinpoint the correct tissue during the process, minimizing damage to the normal tissue. The availability

of cryoablation at Children's National allows us to more safely address all rhythm abnormalities so that complete repair versus medication is an option for most patients.

OUTPATIENT PROGRAM

Children's National Heart Institute **Outpatient Program** provides an extensive range of evaluation and services for children and adults with congenital heart disease. Additional programs include general cardiac evaluation, pulmonary hypertension, congestive heart failure, cardiac transplantation, My Babies Heart (single ventricle clinic), syncope evaluation, electrophysiology, pre-cardiac catheterization and intervention preparation, pre and post cardiovascular surgery evaluations, preventive cardiology, and obesity genetics.

Diagnostic testing and intervention are available using state-of-the-art diagnostic imaging and radiology. Cardiac recovery services provide a specialized, therapeutic environment for congenital heart patients undergoing procedural services requiring cardiac anesthesia and/or sedation.

Outpatient services also include multidisciplinary clinics that provide collaborative services with other departments to maintain the mission of patient focused care. Patients in these clinics receive care in conjunction with specialists from services such as hematology and oncology, genetics, and nutrition.

Children, adolescents, and entire families are given the education and skills needed to correct conditions and to achieve optimal wellness while coping with their congenital heart disease/arrhythmia/ anticoagulation management with a team of premier cardiologists, Magnet nurses and nurse practitioners, and staff from social work, nutrition, and pharmacy.

Outpatient services works collaboratively with the inpatient units to provide patients with family-centered care across the healthcare continuum.

INPATIENT PROGRAM

Inpatient Cardiology on the Heart and Kidney Unit at Children's National Medical Center is part of the progressive and comprehensive care for cardiac patients. While at Children's National, patients and families have access to a team of cardiologists, cardiovascular surgeons, critical care specialists, neonatologists, and nurse practitioners who provide comprehensive medical and surgical care.

All members of the team, which also includes nurses, social workers, nutritionists, pharmacists, and child life specialists, specialize in caring for children with heart disease and their families.

Hospitalist physicians work as an extension of the patient's primary cardiologist, focusing on the medical care of patients who require hospitalization for treatment of a cardiac condition. Hospitalists in the Heart and Kidney Unit are cardiologists with extensive training and experience in providing expert care for infants and children with cardiac conditions. Parents are encouraged to participate in discussions about their child's treatment plan, and are invited to participate in daily team rounds while on the cardiology inpatient unit.

PULMONARY HYPERTENSION PROGRAM

Children's National Heart Institute's **Pulmonary Hypertension Program** offers comprehensive evaluation to determine the cause and treat this rare and complex disease. Pulmonary hypertension (PH) is high blood pressure in the arteries of the lung. PH is not a single disease, but a group of rare and complex diseases affecting the lung's blood vessels. The high pressure in the pulmonary arteries may cause an enlarged heart and eventually cause heart failure. Children's program offers comprehensive evaluation to determine the cause of a child's pulmonary hypertension and individualize appropriate therapy. Therapy could include medications specifically for PH and treatment of underlying disorders. For example, if a child has a ventricular septal defect, closure usually alleviates the PH. As the only dedicated program in the region, the team of several subspecialists closely manages each child's care to create an individualized and appropriate course of treatment.

HEART FAILURE TRANSPLANT PROGRAM

Heart failure is a devastating disease where the heart cannot pump enough blood to the body. It can be caused by cardiomyopathies, where the heart muscle is not strong enough, or complex congenital heart disease with structural defects where surgical options have failed or are not available.

At Children's National Heart Institute we understand that dealing with heart failure is a challenging experience for patients and their families. Our dedicated heart failure team, consisting of physicians, nurse practitioners, nurses, social workers, a pharmacist, and

child life specialist, work intimately with each family to provide the individualized attention that they deserve. This comprehensive team allows us to provide world-class, personalized care for our patients.

Additionally, our cardiac subspecialties provide a wide array of invaluable resources for our heart failure patients. Our electrophysiologists provide critical medical treatment options with the use of biventricular pacemakers and automatic cardioverter-defibrillator devices. Our cardiac imaging laboratory (echocardiography and cardiac MRI), cardiovascular surgeons, interventionalists and cardiac pathologists play a vital role in helping diagnose and making important medical and surgical plans.

When oral medications are not enough, we provide a variety of advanced medical therapies to delay or even avoid the need for a heart transplant. Our patients have had home infusions of inotropic drugs to help support the heart function. As a national leader in ECMO (extracorporeal membrane oxygenation), Children's National Heart Institute offers this advanced cardiac support should the need arise to provide temporary mechanical circulatory support for the failing heart and lungs.

The Children's National Heart Institute (CNHI) has partnered with the Washington Hospital Center (WHC), to establish a premier heart **transplant/heart failure program**. Together with the WHC faculty, CNHI faculty perform heart transplants, along with pre- and post-operative care of patients, providing the highest quality of care. We have a systems-based, multidisciplinary approach in place to provide optimal care for the transplant patient. This process furthers develop the existing collaborations of Children's National and Washington Hospital Center in neonatology, obstetrics, pulmonary medicine, nephrology, and adult congenital heart disease.

CARDIAC CATHETERIZATION PROGRAM

Children's **Cardiac Catheterization Lab** performs more than 500 procedures annually. Our team of cardiac interventionalists possess special expertise with the use of intravascular stents in the treatment of severe pulmonary artery stenosis and other blood vessel abnormalities. In addition, we specialize in the catheter-based device closure of abnormal blood vessels and holes inside the heart.

WASHINGTON ADULT CONGENITAL HEART PROGRAM

Children's has a program solely dedicated to **Adult Congenital Heart Disease**, allowing for continuity of care for adults with congenital heart disease – both survivors of early surgery and newly diagnosed adults. Developed in partnership with Washington Hospital Center, the Washington Adult Congenital Heart (WACH) center is a specialized consultative resource for the care of adults with congenital heart disease. WACH strives to meet the unique needs of patients with congenital heart disease by providing all the necessary resources in one centralized location. Physicians within this program are specially trained pediatric cardiologists who understand the complex issues that arise as survival rates improve for people whose hearts were repaired years ago.

PREVENTIVE CARDIOLOGY

The **Preventive Cardiology Program** is a multidisciplinary program made up of physicians, nurses, and nutritionists. Together we work to improve the diets and lifestyles of our patients to reduce the risk of cardiovascular disease.

Cardiovascular disease, such as stroke and heart attack, is the leading cause of death in adults. We know that the risk factors that lead to cardiovascular disease start in childhood. These risk factors include abnormal cholesterol, hypertension, increased weight, and other risky or adverse lifestyle choices (lack of exercise, tobacco use, etc). The Preventive Cardiology Team at Children's National is actively involved in research on abnormal cholesterol and obesity.

“I saw a pediatric cardiologist throughout my childhood. When I transferred to adult care, they were unfamiliar with cases like mine... Now I see a specialist at Children's National who specializes in congenital heart defects.”

— Derek (an adult patient)





Children's National Heart Institute approaches each patient from the perspective of the family, making decisions based on the health of the child, while also incorporating the needs of the family members.

Cardiovascular Surgery

Children's **Cardiac Surgery** team brings together the region's best cardiac specialists, anesthesiologists, cardiologists, and cardiac intensivists in one setting. Our accomplished team is led by a pioneer in complex congenital heart surgery and early primary repair.

Children's surgeons perform the largest volume of pediatric surgeries in the Washington, DC, area with one of the best success rates for cardiac surgery in the nation. The Children's team performs corrective procedures for newborns, infants, children, and adults.

We often perform surgery when children are very young, so a repair or reconstruction grows with the child and patients and anxious families benefit from a faster recovery. One third of our surgeries for congenital heart defects are performed on children under three months of age.

Procedures range from the most complex congenital problems to the more basic. Our techniques offer patients the best neurological outcomes possible.

Children's National offers a pre-operative and post-operative care clinic for children with complex conditions. A team of pediatric specialists reviews the patient's medical records and develops an individualized care plan prior to surgery to ensure the highest quality of care is delivered.

Cardiac Intensive Care Unit

Children's National is home to a 26-bed unit that features private patient rooms and state-of-the-art technology to monitor patients in the safest environment possible. It is the region's first and only cardiac ICU. The unit is recognized as a Beacon unit for quality and safety by the American Association of Critical Care Nurses. Physicians in the Cardiac ICU are trained in multiple specialties including pediatrics, critical care, cardiology, and anesthesiology. Many are board certified in several or all of these specialties. They are among the nation's leaders in innovative care and clinical research in cardiac intensive care.

The Cardiac ICU features private patient rooms and the layout promotes family-centered care. State-of-the-art technology and techniques, such as rapid deployment of **Extracorporeal Membrane Oxygenation (ECMO)** and **near infrared spectroscopy (NIRS)**, ensure your child receives the most advanced treatment available for young cardiac patients.

Cardiac Anesthesia Program

Children's **cardiac anesthesia** team is exclusively dedicated to anesthesia care to infants, children, and adults with congenital or acquired heart disease. Each member of our team is a board-certified anesthesiologist with subspecialty training and certification in pediatric cardiac anesthesia.

Our team provides care for patients undergoing cardiac surgery, cardiac catheterization, MRI, and echocardiography. They also provide anesthesia care for any patient with significant heart disease undergoing non-cardiac surgery (such as ear tubes and tonsillectomies) or non-surgical procedure (such as dental examination). Team members work closely with the cardiac surgeons, cardiologists, cardiac intensivists, and cardiac nurses who are available 24 hours a day, seven days a week. With such a specialized team, Children's National joins the ranks of the nation's top pediatric medical centers and select children's hospitals.

CARDIAC PROCEDURE RECOVERY UNIT

The Heart Institute's **Cardiology Recovery Services** provides a full service program to meet the individualized needs for inpatients and outpatients undergoing cardiac procedures or anesthesia, including cardiac catheterization and intervention, electrophysiology procedures and intervention, MRI, and sedated echocardiograms and transesophageal echocardiograms. The cardiac anesthesia service is committed to provide a therapeutic environment for clients thereby providing appropriate supplies and equipment in safe conditions for all procedures. Based on a continuum of care, the unit offers integrated pre-procedure, intra-procedure, and post-procedure care.



“From the moment we arrived in the Cardiac ICU, we were welcomed with open arms.”

— *Matthew's mom*



Focus *on the Family*

FOCUS ON THE FAMILY

Children's National Heart Institute features several services for enhanced family-centered care because we understand that when a child is sick, the whole family is affected. Parents are encouraged to:

- Participate in daily rounds to discuss their child's care plan.
- Join the Family Advisory Board, a group of parents who work together with the staff to develop family-centered care initiatives.
- Enjoy a day at the National Zoo during the annual Heart Institute Fall Festival. The Fall Festival is an opportunity for patients, family members, and staff to reconnect with old friends and make new ones.
- Give siblings the benefit of a program designed just for them. The Siblings Are Special Too Program is a chance for siblings to meet with a social worker and child life specialists as well as other siblings and complete age and developmentally appropriate activities.
- Keep family and friends informed by creating a personal website via Caring Bridge. Caring Bridge is accessible on the Children's National website and allows parents to post updates, pictures, and hospital information during their child's hospitalization.
- Introduce their adolescent patient to others with similar experience through the Adolescent Support Group. The group, which is open to adolescents with complex congenital heart disease and implanted devices, meets monthly and offers adolescents the chance to discuss their unique concerns.
- Learn how to bond and comfort their hospitalized infant by participating in the Comforting Your Hospitalized Infant class. This informative class is led by child life specialists and includes information on positive touch, infant massage, and bonding issues.

- Get advice from other families who have been through similar situations through the Parent Letter Project (www.AParentsLetter.org).
- Visit www.ChildrensNational.org to learn about Children's National's experienced and committed team of pediatric specialists.

Moreover, Children's National Heart Institute has a dedicated team to support families – from near and far. The team, consisting of clinical social workers, child life specialists, and concierge service professionals, are available to provide whatever support or assistance you may need before, during, or after your child's hospitalization. From supportive counseling, resource referral, procedure preparation, access to business support services and much more. Our team is ready to help.

At Children's National, we understand that the caliber of medical expertise we offer is often unparalleled, and so, families from around the world seek care for their children here. The International Program was developed to assist families with every detail, from travel arrangements and necessary documentation to culturally sensitive accommodations during your time in the hospital. Because the hospital is located in the heart of the nation's capital, we have the unique advantage of resources in our city to welcome international travelers. We contact embassies, identify translators, and coordinate medical appointments – all in an effort to simplify your stay.

CHILD LIFE SPECIALISTS

Child life specialists are professionals who are specially trained to help children and their families understand and cope with hospitalization, illness, and treatment. Child life specialists:

- Can help to prepare a child and family for a procedure, diagnostic test, surgery, or painful experience.
- Use medical play, teaching dolls, our puppet, “Megan” (designed for cardiac patients), real or play medical equipment, and actual pictures of the rooms and staff. Medical play sessions give your child an opportunity to role play, rehearse, and discuss the various things they will experience ahead of time.
- Provide ways to ease your child’s fears by teaching them relaxation techniques, and provides support and comfort before, during, and after procedures.
- Encourage your child to continue to play while in the hospital in order to promote recovery, normal development, and independence.

There is a playroom for your child to play and participate in activities, such as our pet visitation program.



CAMP HEARTBEAT

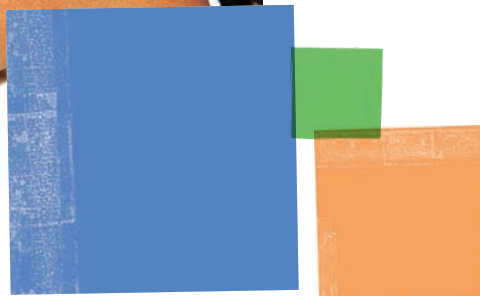
Camp Heartbeat offers children and teens with congenital heart disease, pacemakers, or arrhythmias, ages 7-16, four days of summer fun, education, and social connections in a safe and supervised environment. In addition to fun, the goal of Camp Heartbeat is to reduce the social isolation that is often associated with a heart disorder, and increase the campers’ knowledge and understanding about their condition.

Campers participate and choose from activities including hiking, arts and crafts, canoeing, team sports, a ropes confidence course, and swimming. Support groups and educational programs promote knowledge, skill development, and social connections.

Camp Heartbeat was developed by the Children’s National Heart Institute in collaboration with Children’s National’s Brainy Camps.

“The compassion and care provided, not just to Owen, but to our entire family, is something for which we will be forever grateful.”

— Owen’s mom and dad



Our *Research*

Children's Research Institute (CRI), part of Children's National Medical Center, works to solve the puzzles of disease that affect children and effect positive outcomes through community health programs, clinical trials and experimental therapeutics. The research groups at Children's have increasingly become a focal point for multi-institutional projects in the Washington, DC area, with many collaborative projects with nearby institutions. CRI provides cross-disciplinary integration among laboratories and clinics, facilitated by the high concentration of physician-scientists and the physical proximity of research space and patient care units.

With respect to cardiology, Children's basic science research goal is to determine what causes congenital heart defects in children. Factors such as genetics and environment are currently being investigated. Clinical research also is being conducted on catheterization laboratory devices, as well as the pathophysiology of autonomic disorders.

One of the major accomplishments in pediatric cardiovascular surgery research has been the optimization of neurological outcomes. Prospective randomized surgical trials led to changes in heart-lung bypass procedures that limit the potential for brain damage during surgery and improve the quality of life for our patients. In addition, our lead surgeon pioneered efforts to correct complex congenital heart defects on infants, preventing secondary organ damage. Advancements have expanded the benefits of surgery to young babies, many of which are performed on children younger than three months of age.

Contacting *Children's National Heart Institute*

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"We realize that we are very lucky we live so close to one of the best children's hospitals."

— Joshua's mom



