A Fulfilled Life

Dr. Collazo and his very experienced surgical team performed a complex repair procedure to restore normal blood circulation to Adele’s heart. They reconstructed the pulmonary veins in the proper position, closed off the abnormal connections between blood vessels and veins, and closed the atrial septal defect. The surgery was a complete success.

When she saw her daughter in the intensive care unit, Kim recalls a “symphony of medical paraphernalia” surrounding the infant. A tangle of tubes and wires covered every patch of skin. But she noticed something else as well — for the first time in her life, Adele was moving like a normal baby.

Today, she is a healthy, thriving 15-month-old, who loves to go out, meet people and play with her three-year-old sister, Lilly. “She is so beautiful, with such personality and attitude,” says Kim. “She has a thirst for life. If she didn’t have that drive imagine how different things would be today.”

About Inova Children’s Hospital

Inova Children’s Hospital is Northern Virginia’s only children’s hospital. Our 186-bed, full-service children’s hospital offers a complete range of services and care from more than 35 pediatric specialists including cardiology and cardiac surgery, gastroenterology, hematology/oncology, nephrology and kidney transplant, general surgery and radiology.

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The family is eternally grateful to Dr. Collazo and the entire Inova Children’s Hospital team for saving Adele’s life. “They gave us our daughter back and we will forever carry a piece of them in our hearts,” Kim says. “It’s amazing to think that if this had happened in the past, our child would have died. But today she can be fixed and treated and go on to live a very fulfilled life.”

Kim Spitz

From the moment her daughter Adele was born, Kim Spitz knew something was wrong. The baby was sluggish. She struggled to eat. She rarely cried. Doctors reassured Kim and her husband Doug that everything was fine.

“Nobody seemed to take our concerns seriously,” Kim says. After numerous, a pediatrics finally detected a heart murmur. Adele needed to go straight to the Emergency Room. Stunned, Kim and Doug rushed the infant to Inova Children’s Hospital, where Jin Park, MD, one of Inova Children’s pediatric cardiologists, performed an echocardiogram and delivered a devastating diagnosis: Adele had total anomalous pulmonary venous return (TAPVR), a rare congenital malformation in which all four pulmonary veins do not connect normally to the left atrium. Her heart was obstructed and dangerously enlarged. She would need surgery urgently to repair the defect.

Adele was born, Kim Spitz knew our child would have died. But today she can be fixed and treated and go on to live a very fulfilled life.”

Kim Spitz

Adele for open heart surgery, Kim collapsed in Doug’s arms. “It was just about the most grueling thing we could have imagined,” she says. Adele was born with a rare congenital heart defect — with excellent results. Their confidence buoyed Dr. Collazo, MD, rallied to provide reassurance and support. They had performed this type of procedure many times before — babies just as small — with excellent results. Their confidence buoyed the couple in the face of Adele’s procedure. But as nurses wheeled away their one-month-old daughter for open heart surgery, Kim collapsed in Doug’s arms. “It was just about the most grueling thing we could have imagined,” she says.

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The little girl spent the first few weeks in the hospital, gaining strength and weight. Finally, Kim and Doug were able to take their daughter home to Aldie, where she continued to astound her family with her rapid progress. Today, she is healthy, thriving 18-month-old, who loves our child would have died. But today she can be fixed and treated and go on to live a very fulfilled life.”

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### Research Focus
Researchers from the Inova Translational Medicine Institute are focusing on discovering unknown genetic indicators for congenital anomalies in the study Incidence and Burden of Congenital Anomalies, Genetic Disorders and Genetic Susception on the Neonatal Intensive Care Unit. The goal of the study is to identify genomic and molecular factors that have significant linkage to congenital anomalies and disorders in neonates and children that have not been answered by traditional genetic testing. The basis of the study is the trio-based whole-genome sequencing of the child and both parents.

### Ongoing Studies
- **Closure of Atrial Septal Defects with the Amplatzer Septal Occluder**
  - James Thompson, MD
- **Contegra Pulmonary Valve, HDE**
  - Lucas Callahan, MD
- **National Collaborative to Improve Care of Children with Congenital Heart Disease**
  - Hind Raouf, MD
- **Anti-coagulation practices after cardiovascular surgery in pediatric patients in the pediatric intensive care unit with central venous catheter in place from 2009-2011**
  - Charlotte Spolveri, MD
- **Incidence and Burden of Congenital Anomalies, Genetic Disorders and Genetic Susception in Neonatal and Pediatric Patients**
  - Joseph Vickery, PhD, and Neale Bigelow, MD

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### Recent Program Achievements

- In 2014, the pediatric and fetal echo program received ICEAL certification. This certification is based on the ACC/AHA Guidelines for Echocardiography Accreditation.
- A testament to the protocol driven approach that the echocardiography technologists and pediatric cardiologists follow each day within the hospital setting.
- This year, the Cardiac Neurodevelopmental Clinic was established to serve the neonates, deep hypoxic encephal failures, and cardiac ECMO patient population. Each child is seen by a neuropsychologist, who determines if additional support services such as physical therapy, occupational therapy, speech or specialized school services are needed.
- The 2014 Star Kids Fun run, which supports the Inova Children’s Hospital Neonatal Intensive Care Unit, where most of the cardiac patients spend their first few days—or months—of life has again been recognized by U.S. News & World Report as being among the nation’s top 5 Neonatology programs. The NICU was also recertified by the Joint Commission with the 50 Neonatology programs.

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### Congenital Cardiac Catheterizations Volume: 2010-2014

<table>
<thead>
<tr>
<th>Year</th>
<th>2010</th>
<th>2011</th>
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- **Pediatric Interventional Catheterizations by Type 2010-2014**

<table>
<thead>
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<th>Type</th>
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<tr>
<td>Pulmonary Venous Return (TAPVR)</td>
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<tr>
<td>Atrioventricular Canal Repair (AVC)</td>
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<tr>
<td>Tetralogy of Fallot (TOF)</td>
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<tr>
<td>Ventricular Septal Defect (VSD)</td>
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### Pediatric Electrophysiology Procedures by Type: 2010-2014

<table>
<thead>
<tr>
<th>Type</th>
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### Inova Children’s Mortality Rate as Compared to National Benchmarks

<table>
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<th>2014</th>
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<td>2012</td>
<td>2013</td>
<td>2014</td>
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<td>Atrioventricular Canal Repair (AVC)</td>
<td>27</td>
<td>37</td>
<td>37</td>
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<td>37</td>
</tr>
<tr>
<td>Tetralogy of Fallot (TOF)</td>
<td>27</td>
<td>33</td>
<td>33</td>
<td>33</td>
<td>33</td>
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<tr>
<td>Ventricular Septal Defect (VSD)</td>
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<td>20</td>
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<tr>
<td>Pulmonary Venous Return (PAPVR)</td>
<td>11</td>
<td>11</td>
<td>11</td>
<td>11</td>
<td>11</td>
</tr>
<tr>
<td>Pulmonary Venous Return (TAPVR)</td>
<td>20</td>
<td>20</td>
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<td>11</td>
<td>11</td>
<td>11</td>
<td>11</td>
<td>11</td>
</tr>
</tbody>
</table>

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### Volume and Survival by Surgical Procedure: 2010 - 2014

- **Median Survival in Days**
  - 2010: 27 days
  - 2011: 33 days
  - 2012: 39 days
  - 2013: 44 days
  - 2014: 49 days

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### About Our Program

- The Congenital Heart Program at Inova Children’s Hospital, ranked 47th in the nation in cardiology by US News & World Report (2015-2016), has been caring for the hearts of our region’s children for more than 25 years.
- Our pediatric cardiologists, electrophysiologists, anesthesiologists, radiologists, perinatologists and cardiac surgeons have dedicated their practice to helping children overcome complex congenital heart abnormalities.
- Part of the Inova Heart and Vascular Institute, the Congenital Heart Program is able to provide a lifetime of care, starting before birth through childhood and throughout adult life in the Adult Congenital Program.

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### Inova Children’s Hospital Neonatal Intensive Care Unit, where most of the cardiac patients spend their first few days—or months—of life has again been recognized by U.S. News & World Report as being among the nation’s top 5 Neonatology programs.
Recent program achievements include:

- In 2014, the pediatric and fetal echo program received ICEAL certification. This certification is based on the NICQ Standards and Guidelines for Echocardiography Accreditation. It is a testament to the protocol driven approach that the echocardiography technologists and pediatric cardiologists follow each day within the hospital setting.

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- The 2014 Shoh Kit Fun Run, which supports the cardiac program, succeeded in raising more than $800,000 with 600 runners and walkers.
- The Inova Children’s Hospital Neonatal Intensive Care Unit, where most of the cardiac patients spend their first few days – or months – of life has again been recognized by U.S. News & World-Report as being among the nation’s top 10 neonatology programs.

Inova Children’s Congenital Heart Surgery Volume 2010-2014

Inova Children's Congenital Cardiac Catheterizations Volume 2010-2014

Pediatric Interventional Catheterizations by Type: 2010-2014

Surgical Procedure

Voluntary Septal Defect (VSD)

Valvuloplasty (VSD)

Balloon Occlusion (TAPVR, PAPVR)

Pulmonary Venous Return (PV)

Pulmonary Venous Return (PVR)

Pulmonary Venous Return (PAPVR)

Pulmonary Venous Return (PV)

Pulmonary Venous Return (PVR)

Pulmonary Venous Return (PAPVR)

Pulmonary Venous Return (PV)

Pulmonary Venous Return (PVR)

Pulmonary Venous Return (PAPVR)

Pulmonary Venous Return (PV)

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Volunteer Surgical and Survival by Surgical Procedure 2010-2014

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After numerous appointments, a pediatrician finally detected a heart murmur. Adele needed to go straight to the Emergency Room. Sununet, Kim and Doug rushed the infant to Inova Children’s Hospital, where, Dr. Pan, MD, one of Inova Children’s pediactric cardiologists, performed an echocardiogram and delivered a devastating diagnosis. Adele had total anomalous pulmonary venous return (TAPVR), a rare congenital malformation in which all but one pulmonary vein did not connect normally to the left atrium. Her heart was obstructed and dangerously enlarged. She would need surgery urgently to repair the defect.

Kim and Doug struggled to digest the news. "We were relieved to have an explanation, but also panic and concern seriously," Kim says. "It’s amazing to think that if this had happened in the past, we would have lost our daughter for open heart surgery, Kim collapsed in Doug's arms. "It was just about the most grueling thing we could have experienced," she says. "It was just about the most grueling thing we could have experienced," she says.

When she saw her daughter in the intensive care unit, Kim recalls a "symphony of medical paraphernalia." She looked like a piece of medical equipment being examined. The baby was so small, she says. "She has a thirst for life. If she didn’t have that drive imagine how different things would be today," says Kim.

The family is eternally grateful to Dr. Collazo and the entire Inova Children’s Hospital team for saving Adele’s life. "They gave us our daughter back and we will forever carry a piece of them in our hearts," Kim says. "It’s amazing to think that if this had happened in the past, our child would have died. But today she can be fixed and treated and go on to live a very fulfilled life."