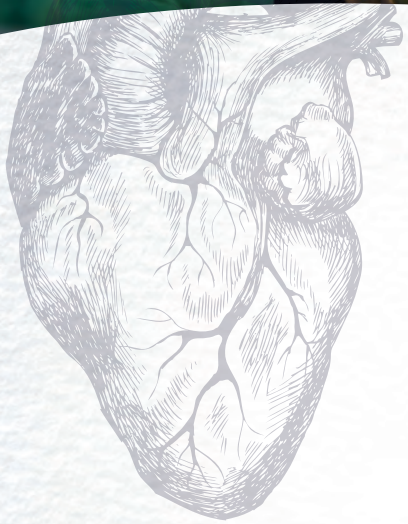


PRIMARY CHILDREN'S HOSPITAL

HEART CENTER

ANNUAL REVIEW 2014

Intermountain®
Primary Children's Hospital

UNIVERSITY OF UTAH
SCHOOL OF MEDICINE

Welcome to the Heart Center

Thank you for your interest in Primary Children's Heart Center.

As the only provider of comprehensive care to children with heart disease in the Intermountain West, we take pride in combining clinical excellence, cutting-edge innovation, and compassionate care to provide world-class treatment.

You'll feel positive energy the moment you step inside our dynamic center, where more than 40 highly skilled physicians all work tirelessly to treat the most complex congenital heart conditions. Our physicians are supported by more than 300 staff members, including medical assistants, physician assistants, nurse practitioners, cardiac sonographers, nurses, perfusionists, respiratory therapists, social workers, genetic counselors, child life specialists, and more. These dedicated professionals provide expertise and contribute significantly to patient care that is aligned with Primary Children's philosophy: *The Child First and Always.*®

Turn any corner and you'll see these team members:

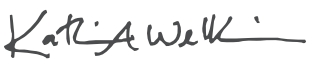
- Performing one of the approximately 500 complex cardiothoracic surgeries that we complete each year.
- Collaborating across department lines to develop innovative new treatments.
- Conducting groundbreaking research on a myriad of subjects to generate material for more than 100 publications, clinical trials, and studies each year.
- Working with the latest technology that saves lives, often utilizing non-invasive methods.
- Counseling family members of patients to ensure that parents are actively involved in treatment decisions.
- Paying close attention to the non-medical needs of our patients and their families.
- Trying to bring a smile to a patient during one of the approximately 13,000 outpatient visits we provide each year.

Our forward-thinking approach to providing care means that we look to innovation—both with technology and through the development of progressive programs—to better serve our patients. For example:

- Our High Risk Program provides closer, more consistent care and follow-up for single ventricle patients during the interstage period between surgeries.
- Our Cath Lab utilizes expertise and advanced technology to perform approximately 800 interventional and electrophysiology procedures each year, making it one of the busiest labs in the country.
- Our Cardiac Genetics Program specializes in the management of patients who have been diagnosed with, or who are at risk of developing, a heritable cardiovascular condition.
- Our Fetal Heart Program greatly improves the care of infants with congenital heart disease through early fetal detection, prenatal planning, and expedient management after birth.

Our ongoing research and educational efforts, along with hard work and expertise, have helped us to maintain an impressive track record of positive outcomes. Even though we are ranked among the best pediatric heart centers in the nation, we are constantly striving to improve. As you read this report, learn more about our programs, and go over our patient outcomes, you can rest assured that we are continually refining the care we provide to ensure that our outcomes are even better today and in the future.

Sincerely,



KATY WELKIE, MBA, RN
CEO, Primary Children's Hospital

LLOYD Y. TANI, MD
Medical Director, Heart Center

PHILLIP T. BURCH, MD
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We firmly believe that our success
comes from adherence to our philosophy of
The Child First and Always.®

The Heart Of The Matter

Healing the physical and emotional components of the heart.

As the hardest-working muscle in the body, the heart never rests as it pumps nearly 200 gallons of blood daily in its constant quest to keep all of the body's systems functioning. Of course, the importance of the heart goes beyond the physical. A heart can sing, cry, smile, and laugh. You can listen to your heart, follow it, break it, change it, cross it, and pour it out. To "have heart" is to be kind, compassionate, and courageous. The heart is celebrated in song and verse, and forever associated with love, making the heart our most vital organ.

Primary Children's Hospital understands both the physical and emotional importance of the heart. That's why our Heart Center has been recognized as the premier provider of cardiac care for children in the Intermountain West and why, increasingly, patients from across the country are referred to us every day. We know that the best way to treat a child's heart is...well, with heart.

Reasons to Smile

A national leader in pediatric medicine and research.

Primary Children's Hospital is a full-service academic medical center and the only Level 1 Pediatric Trauma Center serving children with acute and chronic medical needs in the Intermountain West. Located in the beautiful foothills overlooking the Salt Lake Valley, Primary Children's is the children's hospital of Intermountain Healthcare, and the pediatric specialty teaching hospital for the University of Utah School of Medicine. This unique partnership with the University of Utah makes ongoing pediatric research possible and allows for in-depth training for physicians enrolled in pediatric specialization at the University's School of Medicine.

Primary Children's is ranked among *U.S. News & World Report's* Best Children's Hospitals and has received accolades in *Parents* Magazine Best Children's Hospital report. These high rankings and honors are the result of the tremendous outcomes achieved by our experienced multidisciplinary teams working with state-of-the-art equipment. However, we firmly believe that our success comes from adherence to our philosophy of *The Child First and Always.*® This simple philosophy is central to every decision we make and guides how our staff cares for patients and families. Placing *The Child First and Always*® means that we focus on the emotional needs of our patients as well as their physical needs. It means that we provide age-appropriate explanations of medical procedures, entertaining distractions from painful

procedures, and activities for parents and siblings during hospital stays. It means that we engage each patient in the care they receive, while also meeting the needs of the patient's parents and family members. It means that we maintain an absolute commitment to innovation, to compassionate care, and to ongoing quality-improvement initiatives.

At Primary Children's, we are humbled by the national accolades we receive and extremely proud of the outcomes we achieve, but we are motivated by the smiles we put on children's faces and in their hearts each and every day.

Primary Children's Hospital serves a greater geographic area than any other children's hospital in the United States.

Striving for Excellence

Primary Children's Hospital Cardiology and Heart Surgery is Ranked 20th Best in the Nation

Due to the dedication of our physicians and staff and the absolute commitment to our patients, Primary Children's Hospital has been ranked nationally in seven specialties by *U.S. News & World Report's* 2015-16 Best Children's Hospitals rankings.

Clinical research, surgical survival, ability to prevent bloodstream infections, and recommendations from pediatric cardiologists and heart surgeons were among the factors that gave the Heart Center its high national ranking.

Primary Children's Hospital ranked nationally in six other specialties: Cancer, Neonatology, Nephrology, Neurology & Neurosurgery, Orthopedics, and Urology.

The Primary Children's Heart Center's surgical outcomes are in the top 10 percent compared to other hospitals in the country, top five in clinical research, and one of the best heart centers from a cost-comparison perspective.

Visit *www.usnews.com/childrenshospitals* for the full rankings and methodology. The rankings are published in the *U.S. News & World Report's* Best Hospitals 2015-16 guidebook.

The Five Pillars of the Heart Center

ANESTHESIA • CARDIAC INTENSIVE CARE • CARDIOLOGY
CARDIOTHORACIC SURGERY • NURSING

Five Pillars. Zero Walls.

Traditionally, the different departments in heart centers function as separate entities, with specialists in each field laser-focused on their own area of expertise. Here at Primary Children's Heart Center, we've taken the 30,000-foot-view approach to look at the big picture of how our patients move through the five pillars of our system. This has enabled us to see many things we may have missed had we kept our heads down and our eyes focused solely on immediate tasks.

We discovered that in order to better serve our patients, we needed to remove the walls between departments and foster collaboration—to create an environment where ideas on how to improve care can be freely shared by anyone at any time. In order to facilitate open communication between departments, we bucked the usual organizational structure and created a steering committee to oversee and guide the Center. We've made it a priority that every Heart Center employee in every department understands the needs of each patient, throughout all stages of treatment. We strive to improve quality by eliminating unnecessary testing and procedures, decreasing practice variation, and improving

The bond between departments has grown stronger, and our relationships with patients and their families have grown richer, deeper, and more rewarding.

outcomes and service. We also recognize the value of consistent communication and provide families with common contacts throughout their treatment—familiar faces to guide patients and their families every step of the way.

Our collaborative spirit has paid tremendous dividends, not only in patient outcomes, but in many other areas as well. The bond between departments has grown stronger, and our relationships with patients and their families have grown richer, deeper, and more rewarding. We consider communication with our referring physicians to be a priority and are committed to providing timely and optimal information, related to both hospitalizations and outpatient encounters. We understand how important this communication is as patients transition from our care to health care providers closer to home.

It turns out that heart centers can achieve better outcomes—by devising better systems.

Care For the Heart, From the Heart

Primary Children's Hospital Ranked in the Top 15 hospitals in the Nation
Primary Children's Heart Center Ranked in the Top 10 heart centers in the Nation

Parents magazine worked with the Children's Hospital Association to conduct an extensive survey to rank the best children's hospitals in the country. The rankings are based on treatment success rates, safeguards to prevent medical errors, research studies, doctors' experience, community outreach, and support services that address the emotional needs of families.

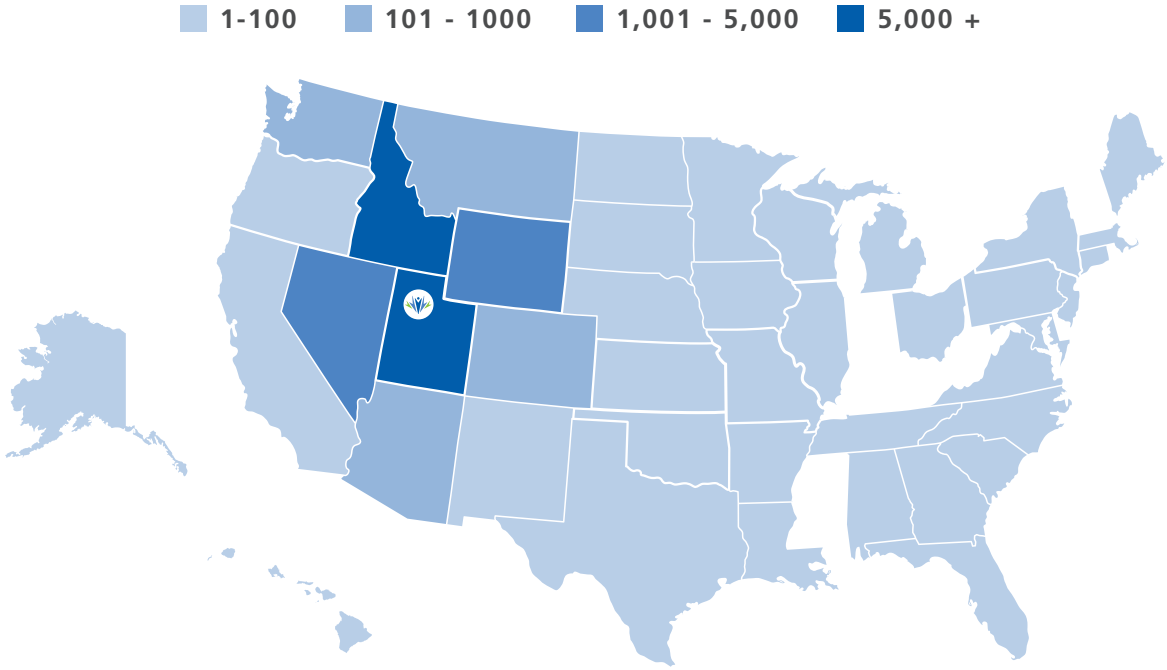
Building on the legacy of clinical excellence at Primary Children's, the Heart Center provides innovative, collaborative care to treat both the physical and emotional needs of heart disease patients, while also meeting the needs of their families.

Primary Children's was ranked as the 15th Best Children's Hospital nationwide with the Heart Center ranked in the top 10. See the March 2013 issue of *Parents* or visit *www.parents.com/health/doctors/best-childrens-hospitals* for the full results of the survey.

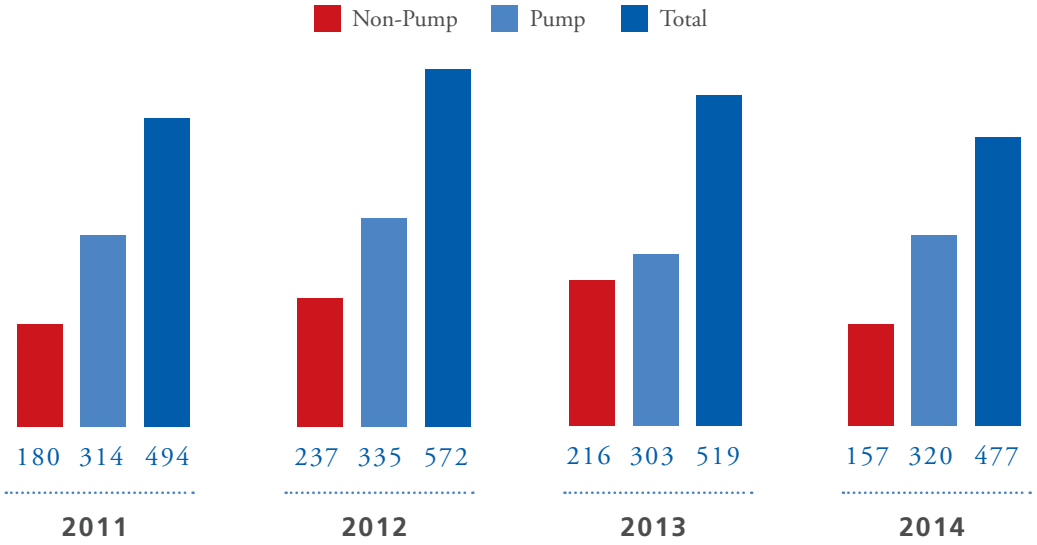
Heart Center 2014 Volumes

Care for Patients Ranging from Newborn Into Adulthood

THE HEART CENTER PROVIDES CARE FOR PATIENTS FROM 42 STATES



ANNUAL CARDIOTHORACIC SURGERIES



16-BED DEDICATED CARDIAC ICU

2 DEDICATED OPERATING ROOMS FOR CARDIAC SURGERY

2 DEDICATED BIPLANE CARDIAC CATHETERIZATION SUITES

MORE THAN 13,000 OUTPATIENT CLINIC EVALUATIONS

MORE THAN 13,000 ECHOCARDIOGRAMS READ PER YEAR

MORE THAN 700 FETAL ECHOCARDIOGRAMS PERFORMED ANNUALLY

PRIMARY CHILDREN'S HOSPITAL STATISTICS

208

AVERAGE DAILY INPATIENT CENSUS

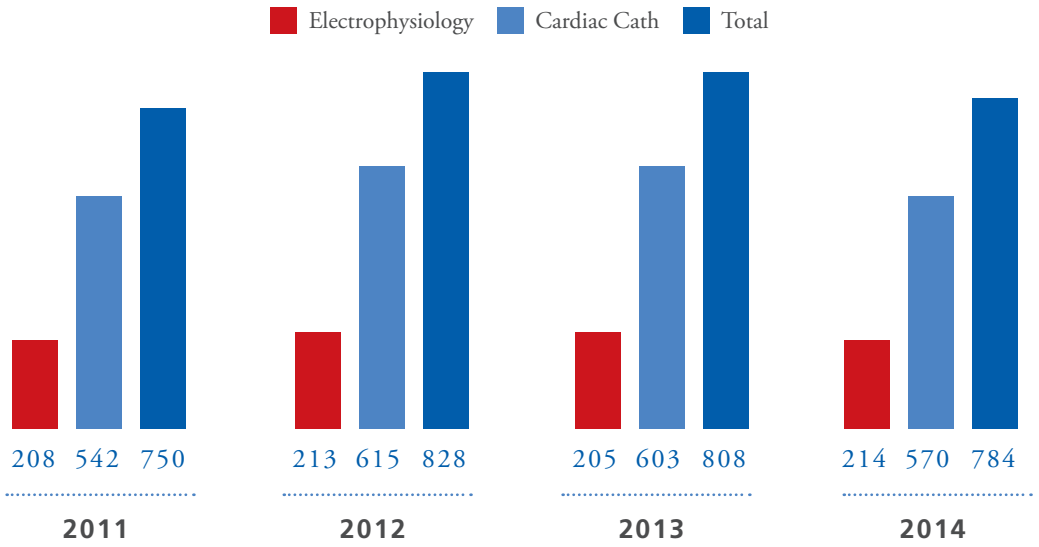
1,042

MEDICAL STAFF

3,300

HOSPITAL STAFF

ANNUAL CATH LAB PROCEDURES



Cardiothoracic Surgery

Increasing knowledge, improving care, and saving lives.

Our Cardiothoracic Surgery Program is one of the most distinguished in the United States. Each year, our surgeons perform hundreds of heart surgeries, ranging from correction of simple heart defects to major repairs of the most complex conditions, as well as performing Ventricular Assist Device (VAD) placement and heart transplantation. Our vast experience allows us to perform at high levels and push the boundaries of possibility to achieve impressive outcomes.

Our cardiothoracic surgery team is composed of three board-certified/eligible pediatric cardiothoracic surgeons along with a world-class support team of specialists, exclusively dedicated to patients with congenital heart disease and other rare heart conditions. Because we are an academic teaching hospital, our staff also focuses on our educational mission and has a strong partnership with the University of Utah Thoracic Surgery Fellowship Program, whose fellows and postdoctoral candidates train in our clinics and lab.

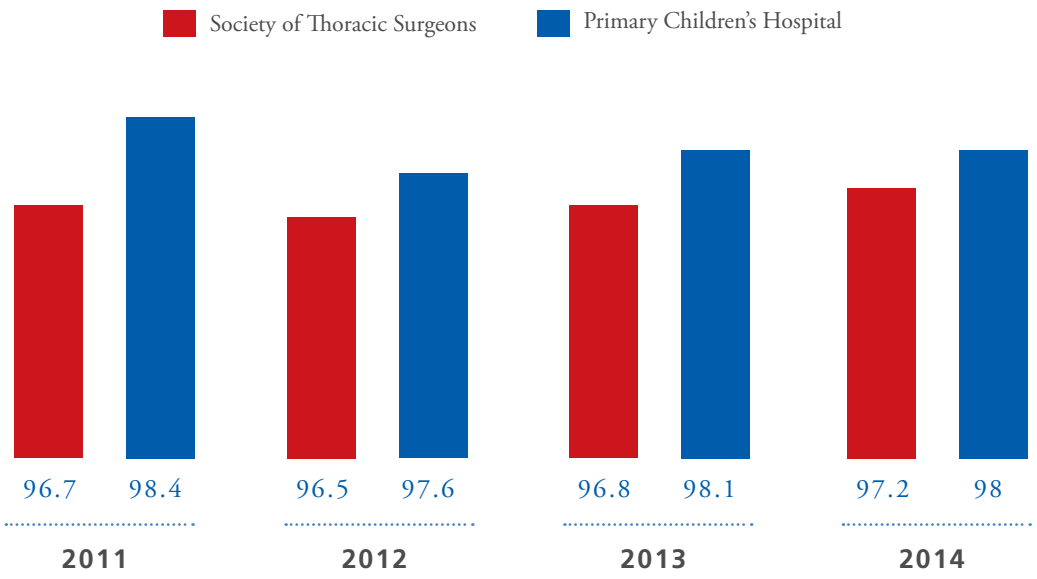
Our collaborative approach enables us to perform a high volume of the most complex surgical cases—with more than 300 cardiopulmonary bypass cases and nearly 500 total cases each year—improving our success rates to historical highs.

We are committed to increasing our knowledge and improving our care through research that spans a myriad of topics including genetics, translational, and clinical outcomes projects. We have active transplantation, VAD, and hybrid programs that are helping to revolutionize our capabilities and the way we provide care.

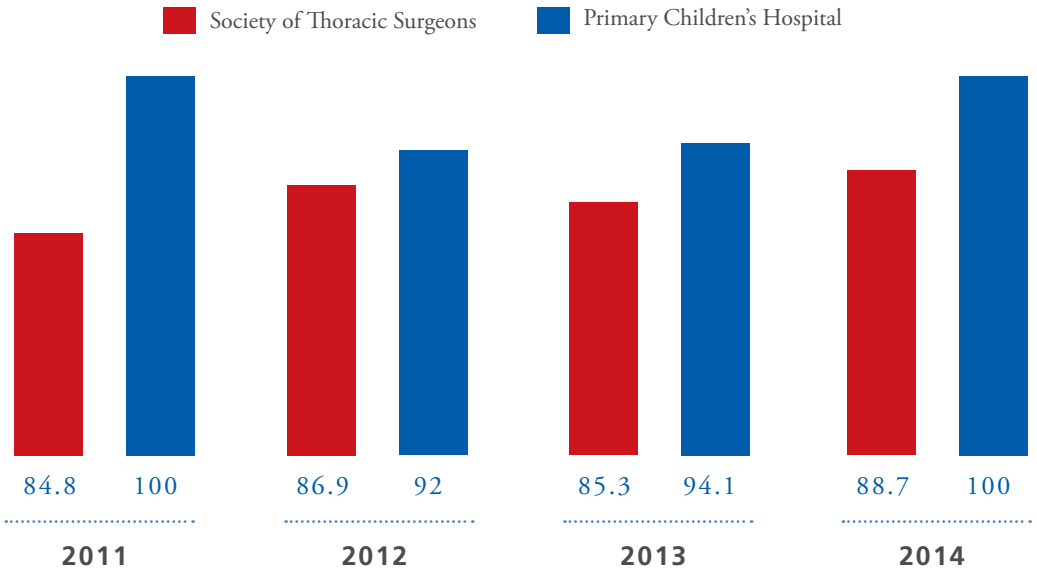
Our commitment to collaboration and innovation can be seen through the wide range of topics covered in the hundreds of articles our physicians and staff have published in influential journals. However, it is best evidenced by the ways in which our team pioneers new care models and consistently refines the methods by which we treat heart diseases.

CT Surgery 2011 – 2014 Survival Rates

CARDIAC SURGERY SURVIVAL RATE — OVERALL

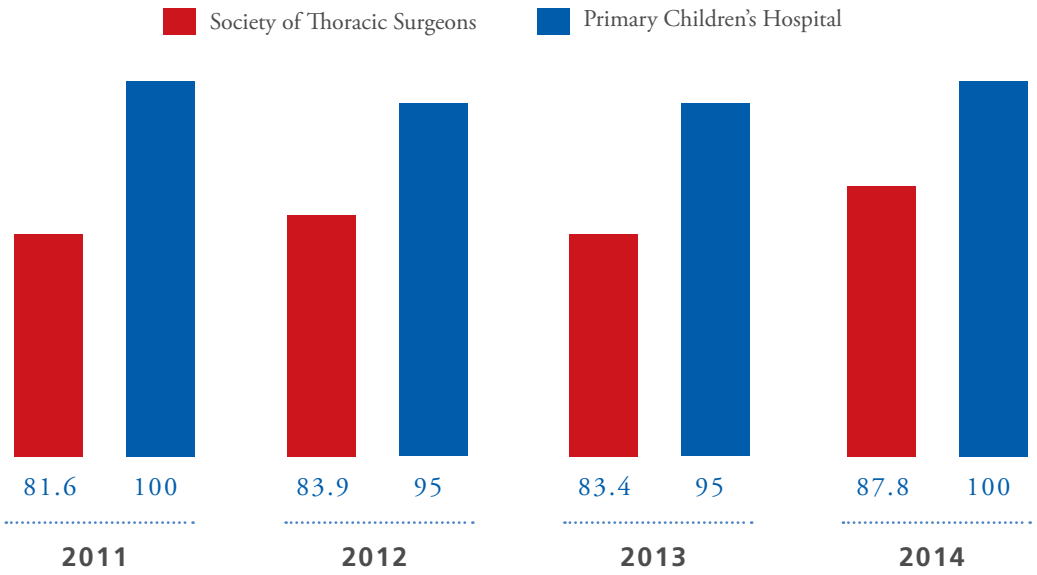


NORWOOD OPERATION SURVIVAL RATE

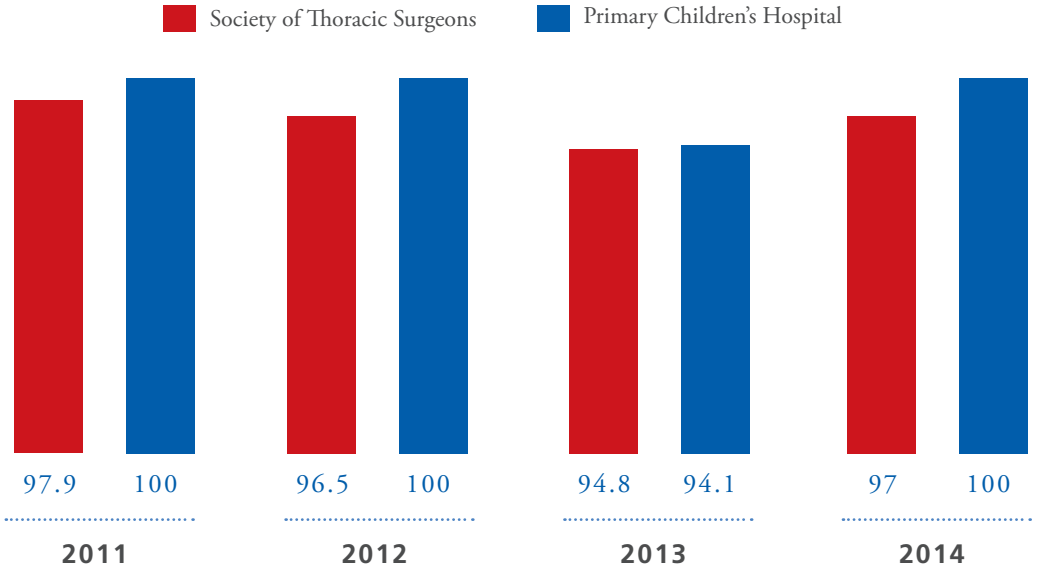


CT Surgery 2011 – 2014 Survival Rates

CARDIAC SURGERY SURVIVAL RATE — RACHS 5-6



ARTERIAL SWITCH OPERATION SURVIVAL RATE



Pediatric Cardiology

Every 15 minutes a baby is born with congenital heart disease

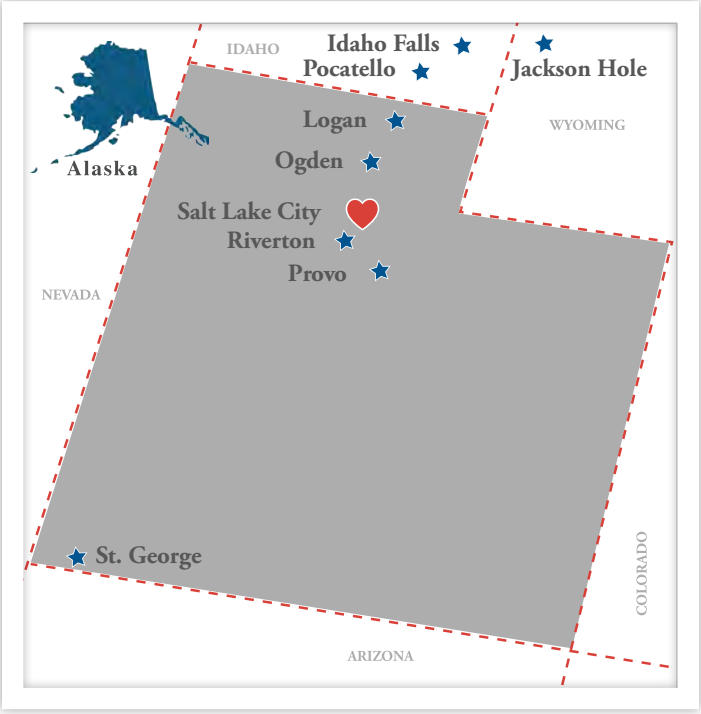
The Heart Center's Pediatric Cardiology Program is one of the best in the country, and provides comprehensive, state-of-the-art evaluation, diagnosis, treatment, and long-term follow-up care for infants, children, adolescents, and adults with multiple types of acquired and congenital cardiac conditions. We strive to provide patients with outstanding care that integrates clinical expertise with access to a vast array of services, innovative technologies, clinical trials, and cutting-edge research.

Our successful track record comes from the expertise and dedication of our closely-knit multidisciplinary team of more than 25 cardiologists and a large staff of nurse practitioners, physician assistants, nurses, administrative assistants, cath lab and echo lab staff members, medical assistants, social workers, pharmacists, genetic counselors, schedulers and others, who work collaboratively to provide personalized care for each patient. Our team regularly communicates with referring physicians and patients' families to coordinate the details for every child's care. We understand the vital role of referring physicians and work to return patients to their care as quickly as possible.

In addition to seeing patients at Primary Children's Hospital, we have regular outreach clinics throughout the state of Utah, Southern Idaho, Wyoming, and Alaska. Subspecialty clinics include:

- Adult Congenital Heart Disease
- Single-Ventricle Survivorship
- Heart Failue and Cardiomyopathy
- Transplant
- Marfan/Aortopathy
- Fetal Cardiology
- Pulmonary Hypertension
- Electrophysiology and Inherited Arrhythmias
- High Risk (interstage single ventricle infants)
- Cardiac Genetics

As an academic program, we are very committed to contributing to the field through basic science, translational, and clinical research. We have a team dedicated to research, with multiple ongoing studies and many publications as evidence of our efforts and commitment in this area. We also have a thriving fellowship training program in pediatric cardiology, with the goal of training those who will go on to provide excellent care and become future leaders in our field.



Cardiac Intensive Care

The highest level of care for even the smallest heart patients.

The Cardiac Intensive Care Unit at the Heart Center provides an extraordinarily high level of care for newborns, infants, and children with both congenital and acquired heart conditions. Our multidisciplinary team of physicians, nurses, and specialists has extensive training in caring for patients with cardiac disease in an ICU environment and is among the nation's most experienced. We focus on helping patients heal as quickly as possible so they can be transferred out of the Cardiac ICU and onto recovery.

Equipped with the most advanced technology and designed to be a comfortable, parent-centered environment, the 16-bed unit is conveniently located close to the operating rooms, ensuring a smooth transport and effective transfer from the surgical team to the intensive care team. Parents will be close to their child at all times. Comfortable chairs are provided in the unit, and family waiting areas are just steps away.

The 16-bed Cardiac ICU is an exceptional resource that is not available in many children's hospitals. Our Cardiac ICU contributes significantly to our ability to provide patients with innovative, lifesaving care and achieve excellent outcomes.

171
(295)
72/51 (60)
(295)
100

Cardiac Anesthesia

The care goes beyond the bedside, even when you can't see it.

The Heart Center's cardiac anesthesia team provides anesthesia for all diagnostic, interventional, and surgical procedures for children with cardiac defects. Staffed by a group of highly experienced, board-certified pediatric anesthesiologists, the team works closely with our surgeons and cardiologists to ensure that each patient is safe and comfortable during each procedure.

Throughout heart surgery, when patients are heavily sedated, the team monitors all vital functions, including blood pressure, temperature, heart function, and oxygen levels in the blood. Anesthesia team members follow patients throughout their procedure until they are transferred to the care of the Cardiac ICU or the recovery room team.

Of course, the work of the anesthesia team starts long before the operating room and continues well after the procedure is complete. A member of the team meets with patients and their families prior to every procedure to discuss the anesthetic plan, to answer questions, and to help determine whether the patient is physically ready for the operation. Our team is also closely involved with post-operative pain management, working to ensure that patients are comfortable throughout their time in the Heart Center.

Cardiac Nursing

Passion, experience, and personalized care.

The cardiac nurses at the Heart Center are passionate about their work, with the expertise to provide developmentally appropriate, personalized care. They are highly invested in their roles as educators for patients and their families. More than 25 nurses with advanced degrees, including nurse practitioners, clinical nurse specialists, and nurse educators practice within a collaborative model among physicians, respiratory therapists, child life specialists, social workers, and professionals from other disciplines. We foster open discussion with our patients and their families and pursue the overriding goal of sustaining an effective healing environment that meets each child's physical and emotional needs.

Evidence-based practice and nursing research are important parts of our cardiac nursing practice. Cardiac nurses in all roles are actively engaged in research and discovery on vital topics that will lead to improved care.

Cardiac Genetics Program

15-25% of the heart defects in children can be traced to genetic causes.

Our Cardiac Genetics Program offers a multidisciplinary, team-based approach that combines next generation clinical testing with in-depth basic science research to provide our patients with the latest genetic information. We strive to translate this rapidly evolving genetic knowledge into the most advanced clinical care possible.

Our team specializes in the management of families and patients who have been diagnosed with, or are at risk of developing, a heritable cardiovascular condition. Our goal is to incorporate patient genetic information into personalized risk assessment, management, and screening guidelines.

Patients and their families meet with a team of experts, including a dedicated cardiac genetic counselor, a clinical geneticist, and a cardiologist to review medical and family histories, receive a targeted physical examination, and determine the best course of action. This meeting may take place either during their hospital stay or in one of three genetic specialty clinics. This clinical program integrates seamlessly with our innovative Cardiac Genomics Group that is pushing the boundaries of scientific knowledge.

Fetal Heart Program

Heart care begins even before birth.

Approximately 1 of every 125 babies is born with a heart defect. Though heart defects are the most common abnormality, when treated properly, almost all children are able to lead active, productive lives.

Through comprehensive coordination of care among heart specialists, our Fetal Heart Program greatly improves quality of care for babies prenatally diagnosed with congenital heart disease. We focus on early fetal detection and prenatal planning through fetal echocardiograms and consultations with our fetal cardiologists. The program strongly emphasizes family-centered education and counseling to provide recommendations and information about treatment options every step of the way.

Cardiac Imaging

Industry leading technology allows us to more safely treat patients.

The Heart Center's cardiac imaging services provide our patients with a comprehensive diagnosis of cardiovascular disease. We use cutting-edge technology to offer the most advanced noninvasive and minimally invasive approaches in order to limit or eliminate radiation exposure to patients.

Patients benefit from our unique collaboration of experts in all of the cardiac imaging modalities. The team has extensive cardiac imaging knowledge and experience. Our physicians and staff are leaders in many of the cardiac imaging techniques and procedures used by centers across the country.

Services include:

- Echocardiography (2D and 3D, fetal, transesophageal)
- Cardiac Computed Tomography (C-CT)
- Cardiac Magnetic Resonance Imaging (C-MRI)

Pulmonary Vascular Disease Program

With a constantly expanding program and commitment to clinical research and comprehensive care, Primary Children's Heart Center has extensive experience treating pulmonary vascular diseases, including Pulmonary Arterial Hypertension; Pulmonary Hypertension associated with Lung Disease, Liver Disease and Heart Failure; Pulmonary Vein Stenosis, and more.

We understand that the care of children with pulmonary vascular disease is challenging, with complex interactions among the heart, lung, liver, immune system, and blood. Care begins with proper testing to identify the causes and define the severity of the disease. All patients are given every available option to combat their disease, improve their quality of life, and increase their chance for long-term survival. Finally, the program provides support for the physical and emotional well being of patients and their families, offering compassionate care and empowering patients with hope.

High Risk Program

To provide better follow-up and increase positive outcomes for single ventricle patients during the precarious interstage period between the first and second surgeries, the Heart Center initiated an innovative High Risk Program. The program developed several key protocols and comprehensive procedures that the Center follows in order to track patients' weight-gain progress, and to monitor other factors that are key to proper growth and development.

Our Heart Center studied other centers that experienced positive results from similar programs, took what we learned and combined it with our own ideas and expertise to create our High Risk program. Managed with great enthusiasm by three of our experienced nurse practitioners, and overseen by pediatric cardiology, the program gives parents 24/7 access to the nurse practitioners, provides them with important training, and arms them with valuable information.

One of the program's primary focuses is on goals and strategies for feeding. Clinics are set up every weeks for parents to review feeding goals, to learn how to detect early warning signs of trouble, and to cover other important issues like infection prevention. Thanks to support from Intermountain Healing Hearts, our program is able to provide digital scales and oxygen saturation monitors to the parents of every one of our single ventricle patients.

Participation in the program empowers parents to be actively involved in their child's care so they can manage many issues at home without having to come back to the hospital repeatedly or needing to rely on their pediatrician for complex cardiac problems.

Adult Congenital Heart Disease Program

Approximately 90% of those born with Congenital Heart Disease will survive to adulthood.

The Heart Center provides a lifetime commitment to our patients. Because nearly all patients need follow-up care throughout adult life, we offer a full range of inpatient and outpatient clinical services to adults with congenital heart disease and pulmonary hypertension—from diagnosis to cardiac catheterization and surgical repair.

We partner with cardiac experts at Intermountain Medical Center and the University of Utah Hospital to provide optimal cardiac care to adults with congenital heart disease. As the only program in the Intermountain West with cardiologists and cardiothoracic surgeons who are board certified in congenital heart disease, the Adult Congenital Heart Disease Program is devoted to treating patients' physical, emotional, medical, and social needs. We personalize treatment for each patient, providing guidance to individual patients on how their heart condition will affect important touchstones of adulthood, such as employment, pregnancy, and physical activity.

Interventional Cardiology

Our Interventional Cardiology Program draws upon the inventive thinking of our physicians and staff along with exciting new advances in catheter-based technology in order to develop better methods for treating patients. Our dynamic team of cardiologists utilizes new technologies to treat a full spectrum of congenital heart patients—from premature babies that weigh less than a pound to full-grown adults.

The Heart Center's culture of collaboration encourages us to look across departmental lines in order to devise the best possible solution for each patient's unique condition. Our goal is to provide personalized care to treat complex heart problems non-surgically when appropriate, thus reducing the number of surgeries a patient will need over their lifetime. Increasingly, we utilize a ***hybrid*** approach, which combines surgery with a catheterization procedure.

Our innovative methods and track record of success have led us to become one of the busiest centers in the country, performing nearly 600 catheter procedures each year. Our center also works at the forefront of technology through our heavy involvement in device studies and groundbreaking research projects that give patients access to game-changing devices as soon as they become available.

Even though we utilize advanced technology and cutting-edge procedures, we also understand the importance of personalized care and the human touch. Our patients often return to Primary Children's many times for follow-up procedures, so we develop strong relationships with them and their families. We do everything we can to explain procedures clearly, manage expectations, and offer comfort and support.

Melody Valve

With an ongoing commitment to improving the lives of patients with congenital heart disease through innovative treatment options, the Heart Center implemented the game-changing Melody Valve procedure in 2010. The Melody Valve procedure allows a patient's pulmonary valve to be replaced in the cath lab, without open heart surgery. We continue to be the only pediatric program performing the procedure in a five-state area. The outcomes of the procedure have been excellent and extremely beneficial in improving patients' quality of life. Now, rather than facing the prospect of multiple open heart surgeries to replace the failing valve, candidates for the procedure have the option to take advantage of this minimally invasive procedure, which allows them to walk out of the hospital with only a Band-Aid® covering a small puncture on their leg. Our heart experts have completed the procedure more than 100 times and, with more patients scheduling the procedure every week, the Heart Center has grown to become one of the busiest Melody Valve programs in the country.

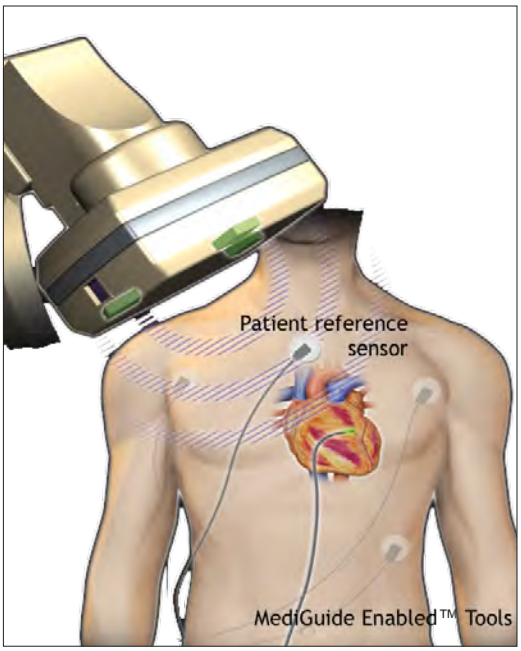
MediGuide GPS Technology

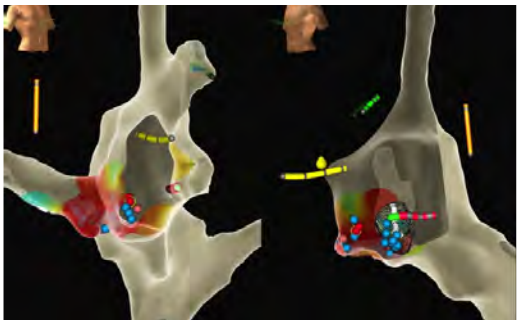
Less radiation and less contrast, with better GPS guidance in the cath lab.

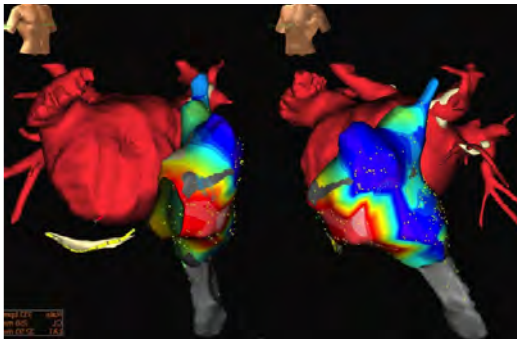
MediGuide Technology provides significant benefits especially during longer interventions or examinations in the cath lab. The cardiologist no longer has to take fluoroscopic images of the patient each time the catheter is re-positioned, as is the case with other current technology. As a result, less radiation and less contrast agent use is expected.

By means of magnetic targeting, MediGuide locates the catheter during cardiac interventions and projects its precise position in real-time on a previously acquired fluoroscopy image of the patient.

Navigation with the MediGuide Technology utilizes a special electromagnetic tracking procedure to determine the position of medical devices during minimally-invasive interventions. During the intervention, a miniaturized sensor integrated into the catheter can be located by receiving electromagnetic positioning signals from the MediGuide transmitters, which are incorporated into the detector housing. The MediGuide Technology then calculates the respective position and orientation of the catheter and displays it in real-time on fluoroscopic images of the patient that were recorded earlier.







Three transmitters in the x-ray equipment identify and show the GPS location on the pre-recorded image of the heart. Mediguide also utilizes specialized software and conduction catheters to re-create 3D models of the heart so physicians can reduce the amount of radiation a patient receives during a procedure.

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Electrophysiology

The most advanced technology to provide the latest treatments.

The Heart Center provides cardiac arrhythmia patients with state-of-the-art evaluation and treatments, including alternatives to daily medication through our electrophysiology services. We have a full-time dedicated electrophysiology catheterization facility, equipped with cutting-edge, integrated monitors and advanced 3D-imaging capabilities. We use the most advanced technologies to provide innovative new treatment methods, including ablations, implantable devices such as pacemakers, cardioverter defibrillators, and cardiac resynchronization treatment (CRT).

Four board-certified physicians and specially trained staff members utilize sophisticated 3D virtual reality cardiac mapping technology to detect electrical abnormalities in the heart without exposing the patient to radiation from X-rays. More than half of the 150 cardiac ablations we performed last year utilized this new technology to completely avoid the use of X-rays. Our specialists are so experienced with 3D mapping that we have trained other heart centers in using the equipment.

Electrophysiology also manages 750 pacemakers and 230 defibrillators, primarily through home remote monitoring, where we follow patients' devices online. Online monitoring allows us to manage all of our patients 24/7, even if they live hundreds of miles from the Heart Center. Knowing that we are with them every step of the way gives patients a comforting peace of mind.

The Heart Center's invasive electrophysiology service has had no unintentional heart block in the last 10 years of ablations and no infections in over three years. We've also been successful in greatly reducing the number of inappropriate shocks in patients who have had ICDs. Nationwide, 25% of patients receive a shock when they don't need it; our Heart Center has reduced that number to 10%, and does more than half of cardiac ablations with zero patient radiation exposure.

Single Ventricle Survivorship Clinic

Providing care that not only extends life, but improves the quality of life.

Children with a single ventricle heart defect are born with one effective pumping chamber instead of two. This defect is a serious condition that requires a lifetime of medical care.

Forty years ago, most babies born with a single ventricle died in infancy. Now, thanks to advances in medical care and technology, most children born with this defect live to adulthood. To survive the first few years of life, these patients often undergo multiple open-heart surgeries and typically have a Fontan operation to allow them to survive with only one pumping ventricle. The challenges don't end there. Patients living with Fontan circulation usually face a reduced life expectancy and are at risk for life-long medical complications that may include liver dysfunction, reduced exercise capacity, abnormal heart rhythm, decreased heart function, reduced bone mineralization, delayed sexual maturation, short stature, abnormal clotting, protein-losing enteropathy, and plastic bronchitis.

Now that survival rates have improved, the Single Ventricle Survivorship Clinic has been established with a new focus—to help single ventricle patients achieve the good health necessary to enjoy life, and to help manage any complications that arise related to single ventricle physiology. Since the health issues that Fontan patients experience can vary and often involve multiple organ systems, the Single Ventricle Survivorship Clinic uses a team approach and involves specialists from numerous medical fields to provide patient-centered, collaborative evaluation and treatments.

The team includes:

- Cardiologist
- Endocrinologist
- Nurse coordinator
- Liver and gastrointestinal disease specialist
- Lung disease specialist
- Nurse practitioner

Based on the individual needs of each patient, the team may also include:

- Hematologist
- Cardiothoracic surgeon
- Radiologist
- Holistic care provider

Based on each patient's clinical condition, tests or studies may be performed. If a patient's primary cardiologist or other health care provider has already performed any of these tests, the clinic may not repeat them.

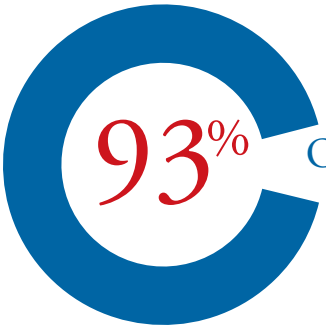
Heart Transplant Program

A leader for more than a quarter century.

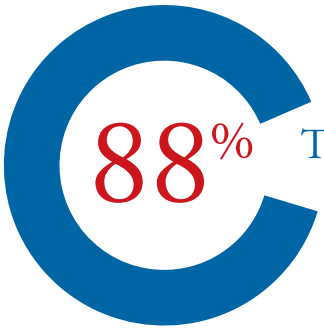
Established over 25 years ago, our Heart Transplant Program consistently achieves excellent patient outcomes, and is one of the most respected heart transplant programs in the country. Our transplant program has performed more than 100 heart transplants in children and has collaborated with a team of experts through the Utah Transplantation Affiliated Hospitals (U.T.A.H.) Cardiac Transplant Program to care for 1000+ heart transplant recipients. Our program brings together a multidisciplinary team of physicians, nurses, social workers, pharmacists, and other support services to provide children with end-stage heart disease the opportunity to grow and develop both physically and emotionally, and to become active members of their families and communities.

A family with a child that needs a heart transplant rides a rollercoaster of emotions, experiencing feelings of hope and determination offset by times of anger, sadness, confusion, and frustration that can be overwhelming. That's why the Heart Center encourages open communication between our multidisciplinary team and patients' families about the process, the progress, and the challenges ahead.

Heart Transplant Survival Outcomes



One-Year Survival Rate
July 1, 2011 – Dec. 31, 2013



Three-Year Survival Rate
Jan. 1, 2009 – June 30, 2011

The Heart Center's heart transplant survival outcomes are among the best in the nation.
To view the report, please go to www.srtr.org

Quality Improvement

At the Heart Center, our physicians and staff of specialists go to work every day with a mission to provide the highest quality, safest, and most appropriate care for our patients. With an unwavering commitment to find new and better treatment methods and procedures, we've achieved tremendous results and have become recognized as a national leader in quality improvement. The Heart Center takes its cue from the culture of quality improvement that permeates Intermountain Healthcare. Led by Dr. Brent James, Chief Quality Officer for Intermountain Healthcare, and one of the foremost quality improvement innovators in the country, Intermountain has a sterling reputation for quality improvement and was applauded by President Obama during a discussion about best practices in health care.

The dedication to consistently refining treatment protocols and measuring outcomes benefits our Heart Center patients in many ways. First and foremost, it ensures that our patients always receive current, high-quality care with proven results. What's more, medical evidence and measured data show that higher quality care tends to cost less, because patients usually experience fewer complications, readmissions, and other issues requiring additional care. To help us measure our performance and improve results, the Heart Center is involved in several quality improvement initiatives. These initiatives allow us to share and compare data with other heart centers across the country so that we can continually refine our treatments to achieve better outcomes for our patients.

Zero Harm Patient Safety Initiative

In partnership with the Solutions for Patient Safety National Children's Network and Healthcare Performance Improvement (HPI), Primary Children's Hospital is on a multi-year journey to become a high reliable healthcare organization. We have termed this initiative "Zero Harm." This approach has implications for the way we view and analyze safety events, the way we investigate causes and the way we organize our units and services for patient safety. The model also requires that every staff member and physician engage in a set of very specific error prevention techniques.

By following the HPI model, Primary Children's Hospital anticipates a 75-80% reduction in serious safety events over the next two to three years. The HPI model has yielded dramatic results for many hospitals. Most have reported reductions of 75% or better in the occurrence of serious safety events. The HPI model has now been adopted by the Solutions for Patient Safety National Children's Network, in which Primary Children's Hospital is participating.

Primary Children's Hospital Heart Center has created a quality improvement committee to foster improvement projects within the Heart Center. The Quality Improvement Committee includes representatives from the five pillars within the Heart Center: Cardiac Nursing, Cardiac Intensive Care, Anesthesia, Cardiothoracic Surgery, Cardiology.

Two recent projects have been undertaken with excellent preliminary results:

1. Duration of chest tube placement decreased after surgery in patients with ASDs, VSDs, AVSDs, and RV-PA conduits older than one month of age on the CSU floor.
2. Improve the process of starting feeds among patients who've had a two-ventricle repair for complex CHD.

National Pediatric Cardiology Quality Improvement Collaborative (NPC-QIC)

With a focus on single ventricle patients, the Heart Center is one of 47 heart centers working with NPC-QIC to improve outcomes for children with cardiovascular disease. We compile and communicate patient information that goes into the database and gain access to the data for hundreds of patients across the country. This allows us to see which treatment methods and feeding protocols are working best for interstage patients. Parents of patients also actively participate in NPC-QIC, sharing ideas on how to further refine protocols in order to maximize the effectiveness of treatments.

National Cardiovascular Data Registry (NCDR*) - IMPACT

The NCDR® is a national repository of cardiovascular data, which provides evidence-based quality improvement solutions for cardiologists and heart specialists committed to measurement, improvement, and excellence in cardiovascular care. The Improving Pediatric and Adult Congenital Treatment (IMPACT) Registry® focuses on pediatric and adult patients who are undergoing diagnostic catheterizations and catheter-based interventions. The collection and analysis of this data is helping to set national treatment standards for patients with congenital heart disease. The Heart Center's participation in the IMPACT Registry® allows us to identify opportunities for improvement and to immediately apply emerging best practices to better serve our patients.

The Society of Thoracic Surgeons (STS)

Our involvement with STS enhances the ability of our cardiothoracic surgeons to provide the highest quality patient care—care that is based on measured data and medical evidence. The STS National Database was established in 1989 as an initiative for quality improvement and patient safety. It has grown to include more than 4.5 million surgical records, which help in creating nationally recognized quality measures and treatment protocols for all types of cardiothoracic surgery, including congenital heart surgery. Our participation in STS also gives us access to resources that help the Heart Center to optimize surgical outcomes.

Utah Population Database

Our research efforts are greatly enhanced by our unique ability to tap into the Utah Population Database (UPD) at the University of Utah—the only database of its kind in the United States. The UPD provides Utah family history data and in-depth demographic information that is used to support research on genetics, epidemiology, demography, and public health.

Pediatric Heart Network and Cardiac Development Consortium

One of the primary sources of our funded studies comes from our participation in the Pediatric Heart Network (PHN). Primary Children's Heart Center is one of nine centers chosen as core sites of the PHN, a collaboration of clinical sites and a data coordinating center that conducts research studies with children who have congenital or acquired heart defects. Created and funded in 2001, the PHN requires centers to compete for five-year grant cycles. The Heart Center has been a core center for all four cycles thus far and is the only core PHN site in the entire western United States, making us one of the nation's leading pediatric heart research facilities. We're also one of only four Cardiac Development Consortium (CvDC) sites in the country. The CvDC is generating — and will share and disseminate — comprehensive data about the molecular networks and pathways that regulate cardiovascular development. The CvDC is building on the current body of knowledge about the underlying mechanisms controlling cardiovascular development by facilitating the collaborative use of current and emerging technologies, and the adoption of common methods of large scale data collection, integration, and analysis.

Leading the Way

The Heart Center's leadership, supported by both Intermountain Healthcare and the University of Utah School of Medicine, has always been dedicated to providing patients with the best and most up-to-date care possible. Our commitment to research plays a vital role in our ability to offer cutting-edge care and has led us to carefully design an infrastructure that allows for quick implementation of the latest research breakthroughs into clinical practice. This, in turn, has led to an impressive track record of being awarded grants to lead research studies on a myriad of subjects. The scope of services that are available at the Heart Center gives us the ability to participate in nearly any kind of study on heart disease.

Basic Science Research

With a focus on understanding the molecular mechanisms that drive both normal and abnormal heart development, our research teams test the theories and principles that go to the source of heart disease, resulting in knowledge that lead to new approaches for prevention, diagnosis, and treatment options. Funded research from the National Institutes of Health and a number of other foundations form the basis of this support.

Translational Research

Driven by the care needs of patients, our translational research is a core part of the research efforts at the Heart Center. As the interface between basic science and clinical medicine, our translational research teams work to appropriately accelerate the results of laboratory studies and clinical trials into new drugs, devices, and innovative new treatments.

Clinical Research

Our team of physicians and staff members includes dedicated researchers who take what they learn from clinical research to the bedside of our patients in order to improve their care. The Heart Center is involved in numerous clinical trials, and our researchers are leading several studies that aim to transform pediatric heart care.

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SCHOOL OF MEDICINE

Family-Centered Care

In addition to providing top-quality medical care, the Heart Center also features a healing environment that supports patients and families through the stresses that illness can cause. We constantly seek feedback from both patients and parents to develop and streamline processes that provide emotional and social support to improve patients' experience. Our Patient and Family Support Services utilize medical social workers, child life specialists, music therapists, inter-faith chaplains, and over 900 volunteers to engage patients and family members with therapeutic activities, positive distractions, and social support to promote physical, emotional, and spiritual healing. We work hard not only to keep our patients alive, but to help them enjoy life.

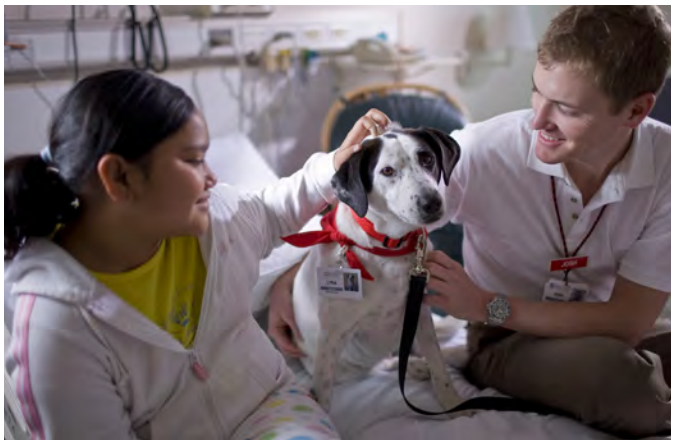
Ronald McDonald Family Room®

This spacious, hospitality-based area on the west side of the hospital offers family members of patients the comforts of home with the added bonus of stunning views of the Salt Lake Valley. The Ronald McDonald Family Room contains washers and dryers, private bedrooms for naps or overnight stays, bathrooms with showers, a business center with computers and internet access, and a beautifully equipped kitchen that's stocked with food. The Ronald McDonald Family Room averages more than 180 visitors each day, with families coming from multiple states. We're also close to the Ronald McDonald House, a more permanent home-away-from-home for families of patients at the hospital.

Music Therapy & Playroom

Music therapy can take place individually in patient rooms or in groups in our dedicated music therapy room, Sophie's Place, which is loaded with guitars, drums, and other instruments. The space was designed to inspire creativity and looks like the world's coolest jam space—it even has a fully functioning recording studio.

Our playroom features toys, books, games, and other activities for children of all ages. This large, colorful play room includes an arts-and-crafts area, a sensory therapy room, medical toys that help children understand procedures, an outdoor patio brimming with plants and fresh air, and a teens lounge with WiFi, computers, and video games.



23 different therapy animals—from a tiny, 3-pound dog to a 120-pound pooch—visit the Heart Center on a regular basis, comforting patients and bringing smiles to their faces.

Spiritual Care

Many people associate Primary Children's with the LDS faith. Like many healthcare facilities, our hospital was started by a religious entity, but Primary Children's is now part of the Intermountain Healthcare network and is no longer affiliated with the LDS church. Patients and their families can rest assured that chaplains are available to individuals, families, and staff members of all religions and faiths, and to those with no faith tradition, but are looking for spiritual strength. Members of the Spiritual Care Team make more than 3000 visits with patients, families, and staff each year. Team members come from a variety of faith backgrounds, including Catholic, Protestant, Latter-day Saint, Jewish, Hindu, Buddhist, Native American, and Spiritual-Not-Religious, to mention a few.

School Services

With strong connections to school districts in a five-state region, our School Services help to ensure that each patient receives proper school instruction while in the hospital. Even after the patient is discharged, we continue to assist with the transition back into school, making sure all the necessary accommodations are put into place to meet the recovering student's ongoing needs.

Primary Children's Language Services conducted over 20,000 medical interpretation sessions in 2014 with interpretation provided in 41 different languages, including Spanish, Nepalese, Mandarin, Arabic, and Portuguese.

In addition to the highlighted services, Primary Children's offers many other Patient and Family Support Services, including:

- Medical Social Work
- Child Life Specialists
- Language Services
- Palliative Care
- Volunteer Services
- Bereavement Program
- Family Advisory Council
- Youth Advisory Council

Heart Center Medical Staff

Venugopal Amula, MD — Primary Specialty: Pediatric Critical Care/Cardiology

David K Bailly, DO — Primary Specialty: Pediatric Critical Care/Cardiology

McKay H. Bateman, MD — Primary Specialty: Pediatric Anesthesiology

Steve Bleyl, MD, PhD — Pediatric Specialty: Pediatric Cardiology

Phillip T. Burch, MD — Primary Specialty: Pediatric Cardiovascular & Thoracic Surgery

Edward B. Clark, MD — Primary Specialty: Pediatric Cardiology

Collin G. Cowley, MD — Primary Specialty: Pediatric Cardiology

Daniel A. Cox, DO — Primary Specialty: Adult Congenital & Pediatric Cardiology

Ronald W. Day, MD — Primary Specialty: Pediatric Cardiology

Claudia Delgado-Corcoran, MD — Primary Specialty: Pediatric Critical Care

Aaron W. Eckhauser, MD — Primary Specialty: Pediatric Cardiovascular & Thoracic Surgery

Susan P. Etheridge, MD — Primary Specialty: Pediatric Cardiology

Daniel A. Evans, MD — Primary Specialty: Pediatric Anesthesiology

David G. Gamboa, MD — Primary Specialty: Pediatric Cardiology

Robert G. Gray, MD — Primary Specialty: Pediatric Cardiology

Benjamin D. Greenberg, MD — Primary Specialty: Pediatric Anesthesiology

Eric R. Griffiths, MD — Primary Specialty: Pediatric Cardiovascular & Thoracic Surgery

James L. Hoffman, MD — Primary Specialty: Pediatric Cardiology

Arvind K. Hoskoppal, MD — Primary Specialty: Adult Congenital & Pediatric Cardiology

Rachel A. Koll, MD — Primary Specialty: Pediatric Anesthesiology

Ashwin K. Lal, MD — Primary Specialty: Pediatric Cardiology

H. Sonali Magdo, DO — Primary Specialty: Pediatric Cardiology

Christopher R. Mart, MD — Primary Specialty: Pediatric Cardiology

Mary Hunt Martin, MD — Primary Specialty: Pediatric Cardiology

Lindsay J. May, MD- Primary Specialty: Pediatric Cardiology

Shaji C. Menon, MD — Primary Specialty: Pediatric Cardiology

Thomas A. Miller, DO — Primary Specialty: Pediatric Cardiology

L. LuAnn Minich, MD — Primary Specialty: Pediatric Cardiology

Kimberly M. Molina, MD — Primary Specialty: Pediatric Cardiology

Thomas A. Pilcher, MD — Primary Specialty: Pediatric Cardiology

Nelangi M. Pinto, MD — Primary Specialty: Pediatric Cardiology

Charles G. Pribble, MD — Primary Specialty: Pediatric Anesthesiology/Critical Care

Michael D. Puchalski, MD — Primary Specialty: Pediatric Cardiology

Elizabeth V. Saarel, MD — Primary Specialty: Pediatric Cardiology

Matthew R. Seely, DO — Primary Specialty: Pediatric Anesthesiology

Jason T. Su, DO — Primary Specialty: Pediatric Cardiology

Lloyd Y. Tani, MD — Primary Specialty: Pediatric Cardiology

Martin Tristani-Firouzi, MD — Primary Specialty: Pediatric Cardiology

Dongngan Truong, MD — Primary Specialty: Pediatric Cardiology

Donald D. Vernon, MD — Primary Specialty: Pediatric Critical Care

Richard V. Williams, MD — Primary Specialty: Pediatric Cardiology

Madolin K. Witte, MD — Primary Specialty: Pediatric Critical Care

Jon S. Woods, MD — Primary Specialty: Pediatric Critical Care

PRIMARY CHILDREN'S HOSPITAL

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