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How I Do It: Tips, Tricks, and Techniques – Implantation of the Alterra Adaptive Prestent and SAPIEN 3 Valve for Transcatheter Pulmonary Valve Replacement

A PICS Society Education Series

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Introduction

The Alterra Adaptive Prestent (AAP) (Edwards Lifesciences, Irvine, CA) is an FDA-approved device designed to prepare the right ventricular outflow tract (RVOT) for a 29 mm SAPIEN 3 balloon expandable valve for those patients meeting criteria for Transcatheter Pulmonary Valve Replacement (TPVR). This device works by internally remodeling the RVOT to create a suitable landing zone for a 29mm SAPIEN 3 valve in those patients in whom a balloon expandable valve alone would not suffice due to the large size and/or irregular nature of the RVOT. It has a self-expanding nitinol frame with PET covering all cells except the distal outflow cells (**Figure 1**). The uncovered cells allow the device to be placed high in the main pulmonary artery, across the pulmonary artery bifurcation, to maintain unobstructed blood flow to the branch pulmonary arteries.

The inflow and outflow diameters of the device measure 40 mm, and the central waist, demarcated with three radiopaque markers, measures 27 mm to accommodate the 29 mm SAPIEN 3 valve. The total Prestent length is 48 mm, with a covered length of 30 mm, which allows the treatment of patients with a shorter RVOT without the need to place a significant amount of the inflow portion of the device within the muscular infundibulum.[1]

The AAP comes loaded in a delivery system with a handle, outer shaft covering the stent that is retracted for delivery, inner delivery shaft with the AAP pre-mounted, and a tapered tip to improve maneuverability through the vasculature (**Figure 2**).

The delivery handle utilizes an ergonomic knob for a slow, controlled deployment. Importantly, AAP can be recaptured up to 70% deployment, allowing for repositioning of the prestent.[2] The entire system fits through a 16 Fr eSheath

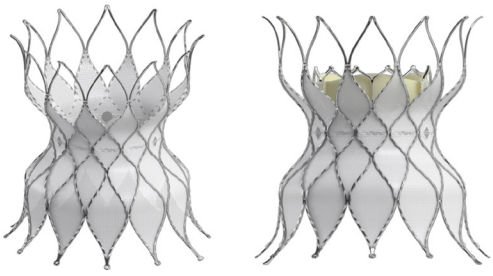

FIGURE 1 *Alterra Adaptive Prestent*

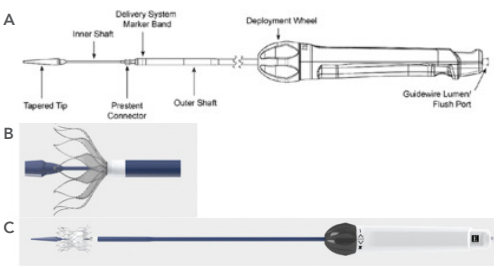

FIGURE 2 *Alterra Delivery System*

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FIGURE 3 *Pulmonic Delivery System*

(Edwards Lifesciences, Irvine, CA), though many operators utilize a larger DrySeal sheath (Gore Medical, Flagstaff, AZ). Following implantation of the AAP, the 29 mm SAPIEN 3 valve is mounted on a Pulmonic Delivery System (Edwards Lifesciences, **Figure 3**) and delivered into the AAP.

The implantation of an Alterra Adaptive Prestent followed by a SAPIEN 3 valve for TPVR requires precise planning and technique. This guide aims to provide insights and practical tips to enhance procedural success, drawing from established best practices as well as our eight-year institutional experience.

TIP 1: Pre-Procedure Planning

Comprehensive Patient Evaluation

Anatomical Assessment: The screening for candidacy for an AAP is performed through data obtained from an ECG-gated CTA. These are detailed reports and include perimeter plots (both systolic and diastolic are provided) assessing coaptation between the inflow and outflow portions of the AAP and the patient-specific anatomy, virtual AAP implants in multiple potential locations, assessments of the branch PAs and coronary arteries, and suggested optimal gantry angles for the procedure (**Figure 4**).

In analyzing the anatomy, one should mentally plan the procedure in advance. These decisions include the preferred branch pulmonary artery (PA) guide wire placement to optimize AAP alignment with the RVOT and ease of delivery, as well as goal implant location in the RVOT and whether the implant will be entirely supra-annular or cross the annulus. Our practice in nearly all cases is to place the AAP with the inflow portion of the device just at or slightly below the previous pulmonary valve annulus, attempting to avoid annular implants that leave a considerable portion of the device in contact with the infundibular myocardium. We believe this may have several advantages including: decreased incidence of peri-procedural ventricular ectopy, allowing for future access to the infundibular isthmus region for ablation if needed, and potentially simpler surgical intervention if needed in the future.

Patient Specific Criteria: Beyond the screening report, one must consider factors such as previous cardiac interventions (e.g., presence of an ostial branch PA stent), the presence of comorbidities, and the patient's overall health status. The goal of any procedure should be to make the best decision for the patient's lifelong care, considering all available options. If deemed feasible, it is our practice to implant a SAPIEN 3 valve alone if the anatomy is favorable for a balloon-expandable valve.

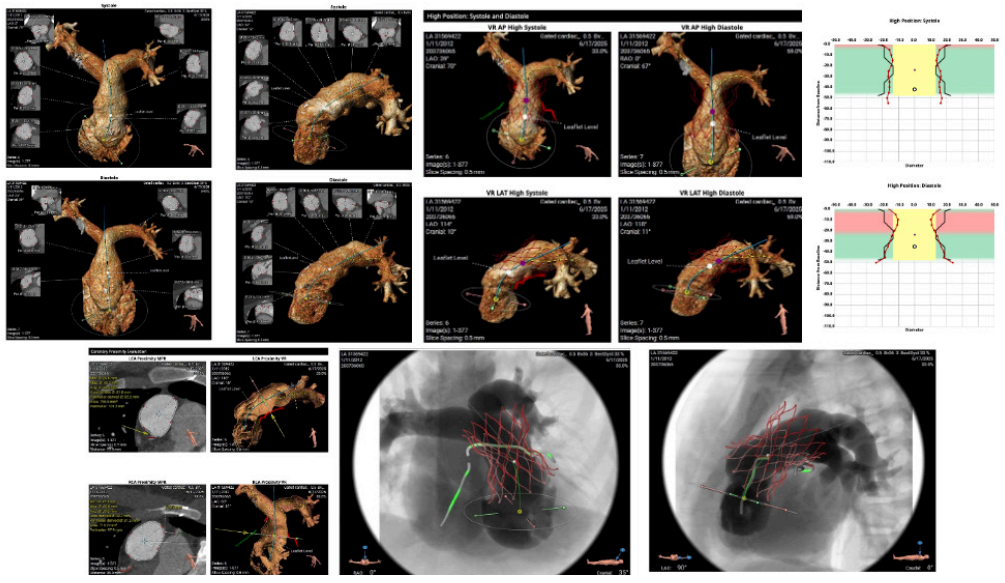
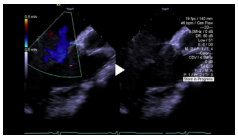


FIGURE 4 *Alterra Screening Report*

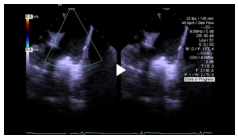
TIP 2: Multidisciplinary Team Approach

Team Dynamics

It's important to assemble a multidisciplinary team to ensure comprehensive care for your patient. Involvement of the entire heart center (interventional cardiologists, cardiac surgeons, imaging specialists, and anesthesiologists) in the planning phase will optimize buy-in from all stakeholders and maximize long-term care and outcomes. Regular briefings and role definition are crucial. Having these discussions outside the laboratory before a crisis will provide the best chance of successfully navigating complications.



VIDEO 1a
Baseline ICE imaging of tricuspid valve



VIDEO 1b
Baseline ICE imaging of RVOT

Case Discussion: Ensure that all team members are aware of what this procedure entails so that complications can be identified early and difficulties can be mitigated.

TIP 3: Implantation Tips

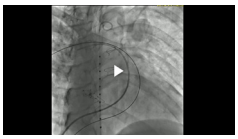
Alterra Adaptive Prestent Placement

Once a patient is deemed to be a good candidate based on the screening report, typically no further testing is needed. However, flexibility during the procedure and the ability to adapt and alter the initial plan are critical to maximizing the chance of a successful implant. The femoral vein (FV) is most typically the preferred access site for the valve implant, but individual patient anatomy (e.g., previous vascular stenoses/ occlusions, tortuous RVOT) must be considered. If tracking of catheters proves to be difficult, the right internal jugular vein is a good option. Our standard initial vascular access consists of

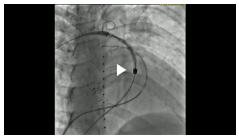
11 Fr. RFV, 5 Fr. RFA, and 7 Fr. LFV. Once vascular access has been completed, all patients receive intravenous prophylactic antibiotics as well as systemic intravenous heparin. Serial ACT measurements are made every 30 to 45 minutes to keep them in the 250s range.

Prior to performing the hemodynamic and angiographic catheterization, it is our practice to perform a complete intracardiac echocardiogram (ICE) to assess the preprocedural degree of tricuspid regurgitation, the presence or absence of any interatrial communication, and the pre-interventional status of the right ventricular outflow tract, focusing on the presence or absence of native leaflets and their location in relation to the potential landing zone.

After obtaining baseline hemodynamics using a 7 Fr. balloon-tipped endhole catheter via the RFV, the wire position is attained in a deep, posterior branch



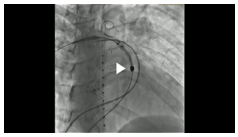
VIDEO 2
MPA angiogram with wire in position



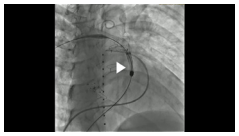
VIDEO 3
Uncovering the initial 25% of device

with a Lunderquist 0.035" guide wire. In most (but not all) anatomies, the right pulmonary artery is preferred over the left as it provides better alignment of the APP with the RVOT. Importantly, a balloon-tipped end-hole catheter should always be used to navigate the right heart to ensure the tricuspid valve is crossed between leaflets rather than risking chordal disruption.

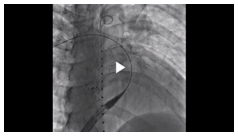
After the stiff guide wire has been placed, an ascending aortogram +/- selective coronary arteriograms may be performed if there are concerns regarding the proximity of the coronary arteries and the intended region of the valve implant. We decide whether this angiogram is necessary on a case-by-case basis. A 7 Fr. Berman angiographic catheter is then advanced via the LFV to the distal main pulmonary artery, and a dense injection is performed using gantry angles predetermined from the CT scan



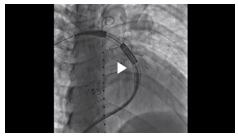
VIDEO 4
Angiogram with 25% Deployment



VIDEO 5
50% Deployment



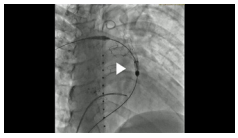
VIDEO 9
Advancement of PDS



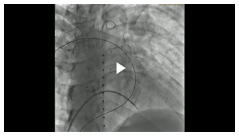
VIDEO 10
Uncovering the PDS

to maximize anatomical understanding of the MPA and RVOT. Areas of focus on this injection include the undersurface of the takeoff of the RPA, the MPA anatomy, presence or absence of remnant valve leaflets and where the MPA transitions in the muscular RVOT.

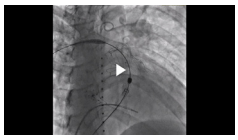
Typically, a team conversation about the desired location of the Alterra implant takes place at this time. Preparing the Alterra simply involves removing it from its packaging and flushing the side port and wire lumen. The 11 Fr. RFV sheath is replaced with a 24 Fr. DrySeal sheath and the Alterra is advanced over the guide wire into the desired location, typically just distal to the final landing zone. An angiogram may be performed at this point as the delivery system may alter the pertinent anatomy.



VIDEO 6
Alterra full deployment



VIDEO 7
Angiogram post-Alterra deployment



VIDEO 8
Removal of Alterra delivery system

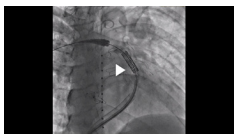
Depending on the anatomy (primarily the length of the MPA), we begin deploying the Alterra by slowly rotating the delivery knob counterclockwise either in the proximal RPA or distal MPA.

Approximately 25-30% of the device is revealed, and another angiogram is performed.

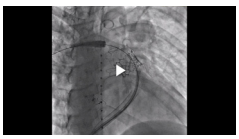
If initial deployment is in the proximal RPA, the entire system is then gently retracted over the wire, allowing the outflow of the Alterra to "flower" open into the distal MPA. At this point, we take another angiogram to determine stent position in relation to the PA bifurcation as well as the angulation of the distal apices to the distal MPA (see below on potential complications).

Additional adjustments may be made to the device position by further retracting the entire system towards the RVOT as deemed appropriate. Note, we do not recommend advancing the uncovered Alterra prestent distally. Once the final position is achieved, the Alterra is fully deployed by completing the retraction of the outer covering.

Following release from the delivery system, the operator should ensure that both proximal retention tabs of the device are free. It is our preference to perform an angiogram after the Alterra implant prior to the delivery system removal.



VIDEO 11
Deployment of SAPIEN 3

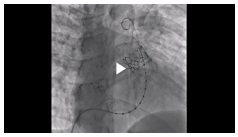


VIDEO 12
PDS removal

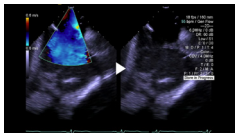
The delivery system is then removed over the guide wire, making sure that the distal portion of the delivery system does not interact with the apices of the device by maintaining coaxial position through the center of the prestent.

SAPIEN Valve Deployment

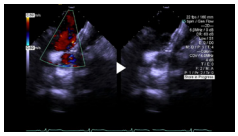
As the 29 mm SAPIEN 3 valve is being mounted onto the Pulmonic Delivery System (PDS), the gantry angles are adjusted to profile the central waist of the Alterra in at least one plane. The 24 Fr. DrySeal sheath and 7 Fr. Berman angiographic catheter in the LFV are removed. The PDS is advanced over the Lunderquist wire directly through the skin and the short in-line sheath that



VIDEO 13
Angiogram after valve deployment



VIDEO 14a
Post-Valve ICE Imaging, evaluating tricuspid valve and pulmonary valve



VIDEO 14b
Post-Valve ICE Imaging, evaluating pulmonary valve

comes with the PDS is advanced into position in the RFV to maintain hemostasis. The PDS is advanced over the wire and into position within the RVOT, such that the valve is located in the midportion of the Alterra utilizing the radiopaque markers on the Alterra as a target.

Slow retraction of the outer sheath of the PDS results in uncovering of the SAPIEN 3. This should be done slowly to maintain the valve in a stable position.

The valve is then deployed in the standard manner using slow inflation to nominal volume.[3]

Using a similar coaxial approach as Alterra, the PDS is removed over the wire to the mid-IVC.

In the mid-IVC, under fluoroscopic guidance, maintaining wire position, the outer PDS sheath is advanced, recovering the balloon until it remarries with the back of the nosecone. The entire system, including the in-line sheath, is then removed over the guide wire and replaced with the 24 Fr. DrySeal sheath. We typically then advance a 5 Fr. pigtail catheter over the guide wire, take a PA pressure, perform a PA angiogram, and get a RV and RA pressure, taking care not to drag the pigtail catheter across the freshly implanted valve.

Following this, it is our practice to perform follow-up ICE imaging where we evaluate any change in tricuspid regurgitation, SAPIEN valve leaflet function, and the presence or absence of any valve or para-valvular regurgitation.

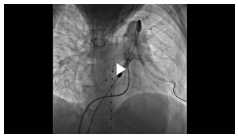
Once this is complete, all sheaths and catheters are removed from the groin and hemostasis is obtained with a combination of manual pressure on the smaller access sites and tightening down of the two previously placed Perclose sutures in the valve delivery site.

TIP 4: Post-Procedure Care

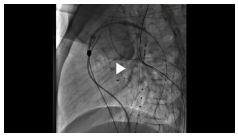
Monitoring and Follow-Up

Immediate Post-Operative Assessment: All patients are kept in the house on a telemetry-monitored bed overnight. It is common for these patients to have frequent premature ventricular contractions after their procedure, and if these are felt to be significant, we will start them on oral beta blockers. Since we have altered our practice to placing the vast majority of these devices in a supra-annular position, we have noted a marked decrease in quantity, severity, and duration of post-procedural ventricular ectopy. More significant ectopy or vital sign instability should prompt stat evaluation of the valve with an x-ray and echocardiogram, and potentially a CTA. In the morning, all patients receive an echocardiogram and an electrocardiogram prior to discharge. A new pericardial effusion should warrant further evaluation of the device with a CTA. All patients at our institution are currently discharged on dual antiplatelet therapy for a minimum of three months, and all are instructed to follow subacute bacterial endocarditis prophylaxis for the lifetime of the valve.

Long-term Monitoring: These patients require lifelong follow-up with continued evaluation of the valve function and right heart parameters. If a significant change is noted in the degree of valve regurgitation or stenosis, our institutional approach is to obtain a 4D CT scan to evaluate for the presence of valve leaflet dysfunction secondary to the presence of microthrombi, which, if present, would prompt a change in antithrombotic therapy.



VIDEO 15a
Malaligned initial deployment (AP)



VIDEO 15b
Malaligned initial deployment (Lateral)

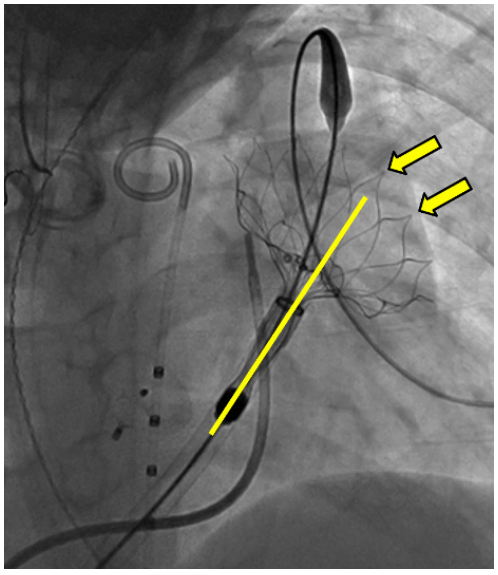
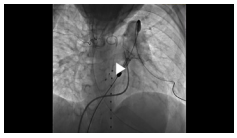
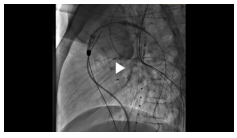


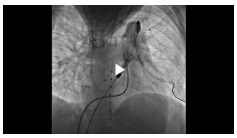
FIGURE 5 *Malaligned initial deployment (AP)*



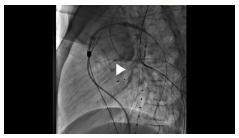
VIDEO 16a
Alterra recapture, AP



VIDEO 16b
Alterra recapture, (Lateral)



VIDEO 17a
Partial re-deployment of AAP with wire repositioning to RPA



VIDEO 17b
Complete re-deployment of AAP with wire repositioning to RPA

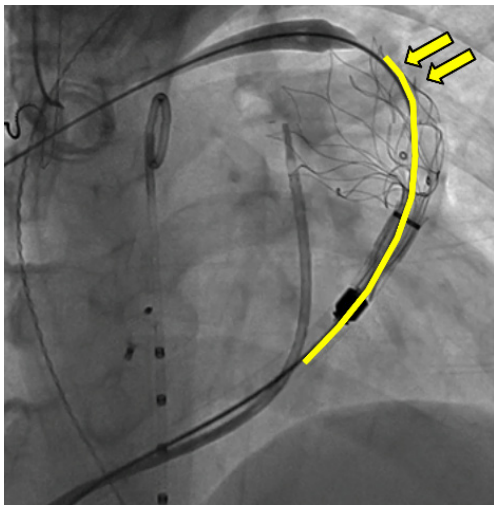


FIGURE 6 *Redeployment of AAP, highlighting appropriate stent alignment within RVOT*

TIP 5: Complication Management

The Alterra Adaptive Prestent has been implanted in over 1500 patients with excellent medium-term results and low rates of complications. However, a key to managing these patients is the anticipation and early detection of complications.[4] As of this writing, we are aware of four known cases of acute perforation of the Alterra apices through the distal MPA resulting in hemopericardium.[5] All cases were recognized prior to hospital discharge, and all patients underwent surgical removal of the device successfully. It is currently believed that this rare complication can be mitigated by ensuring alignment of the device to the curvature of the main pulmonary artery.

While positioning and uncovering the AAP, special focus should be drawn to the alignment of the distal apices of the AAP with the RVOT. If the AAP starts to deploy such that the distal apices are canted leftward (**Figure 5**) and/or inferiorly, it should be recaptured, and an alternative strategy for deployment should be sought.

If the prestent is felt to be too low, the prestent may be recaptured: It can then be redeployed using alternative strategies (e.g., change wire position or landing zone).

Of note, the prestent is easily recaptured when ≤70% deployment, allowing the operator multiple attempts to obtain ideal position.

To date, we are unaware of any instance of chronic erosion resulting in clinical sequelae despite notable concerns about the appearance of the depth of embedment of the device apices into the anatomy.[6] Whether this CT appearance of the device is a desirable design feature which allows for precision placement or is a risk for future vascular disruption remains to be seen, but certainly warrants follow-up and discussion.

Conclusion

The success of an Alterra Adaptive Prestent and SAPIEN 3 valve implantation hinges on meticulous planning, precise execution, and comprehensive post-procedural care. By integrating these tips and tricks, clinicians can achieve improved outcomes and patient satisfaction.

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This article is part of the PICS Society education series - Tips & Tricks for CHD Interventionalists https://www.picsymposium.com/tips_and_tricks_Implantation_Alterra_Prestent_and_SAPIEN_3_valve.html

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Guidelines for Pediatric Heart Failure and the Impact of Clinical Trials

Nadia Chaudhry-Waterman, MD; Shelley Miyamoto, MD; Stephanie Nakano, MD; Benjamin Olsen, MD

Pediatric cardiologists at Children's Hospital Colorado were among the experts who contributed to recently published guidelines for diagnosing and treating pediatric heart failure. While treating heart failure in adults is based on the results of large clinical trials involving thousands of people, there is a lack of data to guide treating heart failure in children. Therefore, these new guidelines for children are valuable but largely based on what we know is effective in adults. Cardiologists and researchers at Children's Colorado suggest that children with heart failure require focused study to improve outcomes.

Updated Guidelines for Managing Pediatric Heart Failure

The International Society for Heart and Lung Transplantation updated their guidelines for managing pediatric heart failure in 2025 — the first update in 11 years. Authors of the updated guidelines included pediatric cardiologists, Shelley Miyamoto, MD, The Selby's Chair of Pediatric Cardiology at Children Colorado, and Stephanie Nakano, MD. Dr. Miyamoto provided insights into why they updated the guidelines.

The update incorporates advancements in pharmacologic therapies and new approaches for evaluating and managing heart failure in children. Because data on pediatric heart failure is sparse, it's more challenging to provide evidence-based guidance on treating heart failure and its complications in children. Dr. Miyamoto says, "While we know many drugs work really well to treat heart failure in adults, it is challenging to know if these same drugs are as effective in children because we do not have large clinical trial data to inform us."

Understanding the Current Approach to Treating Pediatric Heart Failure

Dr. Miyamoto, along with pediatric heart transplant and heart failure fellow Benjamin Olsen, MD, discuss their perspective in the article Pediatric Heart Failure: Current Approach and Treatment. Their comprehensive review outlines the current landscape and future direction in diagnosing and treating pediatric heart failure, emphasizing its complexity, heterogeneity and distinct pathophysiology compared to adult heart failure. Despite lower prevalence, pediatric heart failure is linked to a disproportionately higher burden in terms of mortality, resource utilization and long-term impact.

"The word that stands out is equity," says Dr. Olsen, "and it extends beyond just what we typically would think in terms of ensuring that all people receive the care they deserve — it goes further to ensure that when some have less access to quality care, more effort is put toward ensuring they have sufficient access to address their problem. And this idea extends more broadly into the pediatric heart failure population where again the burden of disease is greater with higher rates of mortality than in the adult population."

Addressing the Inequities in Treating Children and Adults for Heart Failure

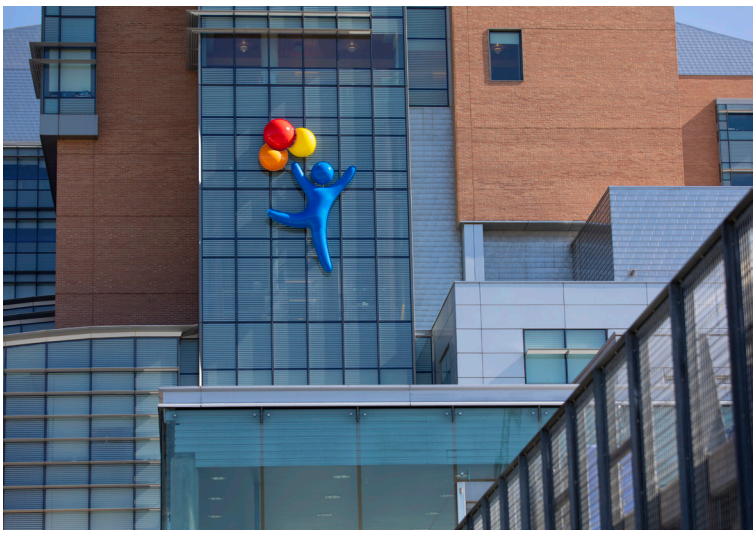
Drs. Miyamoto and Olsen ultimately see the need for more equitable care delivery, improved trial design and targeted research to close the gap in outcomes between children and adults with heart failure.

They also acknowledge that while some treatments may be effective for one population, they may not be effective for all populations with the same issues. For example, while heart muscle failure is a shared pathway in adults and children with heart failure, the mechanisms responsible for heart failure differ between adults and children. This provides potential explanations for why existing heart failure treatment regimens are more effective in adults than children.

"The pediatric cardiology community is very invested in working together and thinking creatively to design studies with children in mind. Novel clinical trial designs and investigations of real-world evidence through harmonizing care across centers are examples of what success could look like in the future. We refuse to settle for 'one size fits all' — children deserve focused study and we are committed to ensuring that happens."

– Shelley Miyamoto, MD

PEDIATRIC HEART FAILURE GUIDELINES AND IMPACT OF CLINICAL TRIALS



Complementary to the new pediatric heart failure guidelines, Dr. Miyamoto and Nadia Chaudhry-Waterman, MD, a graduate of the Pediatric Cardiology Fellowship Program at Children's Colorado, propose ideas for how to combat the inequity in research in the article, Promoting Advancements in Pediatric and Congenital Cardiology Amid Clinical Trial Challenges. Improvements in diagnosing and treating heart diseases diagnosed in infancy or childhood mean that patients are surviving well into adulthood. However, evidence-based guidance for their care has not caught up to the increased life expectancy.

The article cites historical barriers to the success of studies on children with heart disease, as well as highlights some innovative approaches to pediatric heart disease clinical research, which can act as a model for future success. Since the number of children with each heart condition is very small, it is difficult to adequately power studies. Therefore, collaboration is essential and multiple centers must work together and combine their data to effectively study pediatric heart disease treatments.

There is also an increasing number of registry-based prospective clinical trials in pediatric and congenital heart disease (CHD) that can be an effective approach. The collaborative learning network Advanced Cardiac Therapies Improving Outcomes Network (ACTION) started in 2017 with the mission of improving outcomes for children and adults with heart failure secondary to cardiomyopathies or CHD. Children's Colorado participates in this international collaborative, which unites key players, including patients, families, clinicians, researchers and industry.

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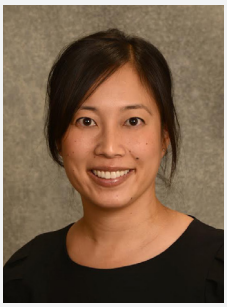

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Transplant Recipient Celebrates Impressive 40-Year 'Heart-Aversary' in a Remarkable Year for Stanford

Lynn Nichols, Stanford Medicine, Heart Center, Patient Stories

Elizabeth "Lizzy" Craze lives life by miles and moments. She ticks off miles one by one while running marathons. She makes the most of every moment—avidly running, strength training, hiking, and swimming—to keep her donated heart beating strong. This year, Lizzy has reached a remarkable milestone: 40 years since her heart transplant as a toddler. Even more remarkable is that she did it with the same donor heart.

Craze Family in the Hospital 1984

"I had my heart transplant at Stanford in 1984. There were not a lot of hospitals in the world doing them on children at that time," says Lizzy. She is the longest-surviving heart transplant patient at Stanford.

Lizzy was diagnosed as a toddler with endocardial fibroelastosis—a rare heart disorder that affects infants and children. It thickened her heart muscle, so that it was difficult for her heart to pump blood throughout her body.

"My family was five for five with heart failure," Lizzy says. "My parents had three children die as toddlers before I was born, and my older brother, Andy, got sick as a teenager. He received a heart transplant at Stanford the year before I did, and when I showed signs of heart failure at two-years-old, he was my biggest cheerleader."

It was 1984—the very start of heart transplants for children under the age of five. Only a handful of transplant centers were trying them on small children, including Stanford. Without a heart transplant, Lizzy would not have survived. She was the youngest heart transplant recipient at Stanford at the time.

50 Years of Pediatric Heart Transplants at Stanford Children's

The pediatric heart transplantation program at Stanford Medicine Children's Health is one of the oldest and largest programs in the world. Lizzy's important 2024 milestone aligns with Stanford's own remarkable milestone of providing pediatric heart transplants for 50 years. It's a big celebration for the Betty Irene Moore Children's Heart Center, the Stanford Children's Pediatric Transplant Center, and the 500+ pediatric patients who have received heart transplants over the years—a rare milestone in itself for a pediatric heart transplant center.

"The field [of heart transplant] was essentially invented here at Stanford, and we are very proud of that," says Michael Ma, MD, Division Chief of Pediatric Heart Surgery at Stanford Medicine Children's Health's Betty Irene Moore Children's Heart Center. Norman Shumway, MD, a Stanford heart surgeon, performed the first successful adult heart transplant in the United States in 1968 and was one of the first Stanford surgeons to perform a heart transplant in a child, in 1974.

Lizzy's heart transplant was performed in 1984 by Philip Oyer, MD, recently retired professor of cardiothoracic surgery at the Stanford School of Medicine. Throughout the years, Stanford Children's gained a reputation for its impressive heart transplant outcomes and vast experience—Stanford Children's is number one in the Western United States in pediatric heart transplant volumes and has performed the highest volume of pediatric heart transplants in California for nine straight years.

Additionally, Stanford Children's is known for its innovative approach to changing the lives of our young patients for the better. For example, since the first successful pediatric heart transplant was performed at Stanford, the heart team has established the first combined heart failure and heart transplant program in the country—Pediatric Advanced Cardiac Therapies (PACT), found creative ways to use adult VADs/Berlin

Woman achieves 40-year anniversary of heart transplant with the same donor heart

hearts in non-adult patients, discovered ways to minimize strokes in small VAD patients, and invented a highly effective donor size matching technique to expand the pool of donors, which earned the hospital the title of one of the most innovative children's hospitals in the nation for its exceptional advances in heart transplant care.

Fast-forward 40 Years

Lizzy, Stanford Medicine Children's Health's oldest heart transplant survivor, hasn't wasted a moment of her life. She graduated from high school and college, got married, landed a fulfilling position in tech, and started a family.

"I definitely try to do everything I want to do and live all the life I can," she says. "I like to say yes to wild ideas."

One of those wild ideas was having a child of her own. Lizzy never thought it was possible, due to her family's serious heart disease. She had accepted this as fact, but then in 2012 her Stanford doctors asked if she wanted specialized cardiovascular genetic testing to see if they could learn what caused all the heart disease in her family. She supplied a sample, and the team found the gene that caused her family's dilated cardiomyopathy.

"At the time of testing, I wasn't thinking about having kids; I just filed the information away. Then, my brother Andy got sick with cancer and died in 2016," Lizzy says. "I started thinking: All of my siblings and parents are gone, but if we had our own family, we could keep the Craze line going."

The couple considered the best way to have a baby. They chose surrogacy with Lizzy's good

friend from college. Lizzy and her husband, Jeff, supplied the egg and sperm via in vitro fertilization.

"We were able to genetically test all the embryos. Out of the four or five embryos we created, there was only one good embryo, and we got lucky," she says.

Today, Elliott, Lizzy's son, is a rambunctious 4-year-old who is always on the move. He just mastered riding a two-wheeled bike. Like his parents, he loves exploring. "He always has a pocketful of rocks," Lizzy says.

Lizzy and Jeff just celebrated their 10th wedding anniversary this year. They enjoy going on adventures together, including traveling to faraway places like Australia, Tanzania, Fiji, Norway, Zanzibar, and Japan. Each Fourth of July the family camps at a lake in California with a large group of friends. This year, Lizzy thinks Elliott is big enough to hike around the entire lake.

Same Donor Heart After 40 Years

The fact that Lizzy hasn't needed a new donor heart in 40 years is also a big reason to cheer. It's extremely rare for a donated heart to last that long.

"I'm up there as far as having continuous use of the same donor heart. There are very few of us who were transplanted in the early '80s and are still alive," Lizzy says.

At the time of her heart transplant, she was expected to survive only five to 10 years, making her achievement downright remarkable. We applaud Lizzy for her dedication to caring for her heart by minimizing infection risk, eating well, and exercising regularly.

"When Lizzy was transplanted, we really didn't know how long a child with a heart transplant could survive. To see that it is 40 years later, and she is doing beautifully, is tremendously encouraging and shows optimism for the future," says David Rosenthal, MD, director of the Pediatric Advanced Cardiac Therapies (PACT) Program and director of the Thoracic Organ Transplantation Program at Stanford Medicine Children's Health.

Lizzy is still getting care at Stanford for her heart, after all these years. When she became a young adult, she transitioned easily to adult heart care at Stanford Health Care. It's one of the reasons her family lives nearby in Menlo Park. At each checkup, she hears that her donor heart is beating strong.

Lizzy planned a big blowout party for her 40th heart anniversary in October.

"We rented a suite at a San Francisco Giants game and invited a bunch of family and friends—even our East Coast relatives are coming," she says.

Living Large, Running Strong

Lizzy has completed 35 half marathons and six full marathons to date. Each one celebrates the chance of a full life after heart transplant. She's currently training for a marathon in Southern California to commemorate her 40-year heart anniversary. "I made a shirt that says, 'I had a change of heart at Stanford Hospital,' on the front, and 'Heart transplant recipient 1984' on the back. I wear it during marathons, and I overhear bystanders remarking on it," she says. Lizzy is grateful for her survival and her sturdy heart.

"I got lucky. There was some magic combo during my heart transplant that worked out for me. Hopefully, this heart will keep me going for another 40+ years."

Scientists Uncover Cellular Mechanism Behind Congenital Heart Defects

Congenital Heart Disease affects approximately two in every 100 newborns globally. But why do they occur?

An important part of the answer may lie in a previously unknown mechanism on the surface of our cells. Researchers from the University of Copenhagen have identified this mechanism in a new study.

The mechanism is located in the primary cilium, a microscopic 'antenna' that protrudes from most cells in the body. The cilium's role is to interpret the body's signaling molecules, enabling the cell to determine whether it should divide, move or die, for example.

In the study, the researchers show that three proteins, TAK1, TAB2 and PKA-Cα, function as a signaling hub within the cell's antenna and play a significant role in heart formation.

"These proteins act as molecular instructions that tell stem cells when and how to develop into heart muscle cells. However, genetic alterations can disrupt this communication, causing 'antenna defects,' which may lead to congenital heart defects," explains Søren Tvorup Christensen, Professor of Cell Biology at the Department of Biology.

Zebrafish and Mouse Stem Cells

In the study, the researchers combined genetic data from patients with experiments in zebrafish, human cells and mouse stem cells to understand how the mechanism works.

First, the researchers analyzed genetic data from several thousand people with congenital heart defects in search of rare mutations. They investigated whether specific genetic changes occurred more frequently in patients than in healthy individuals and therefore were likely to play a role in the disease.

Next, they examined the practical consequences of these mutations. Using genetic engineering, the researchers introduced the same genetic changes into zebrafish and observed their effects on heart development. The experiments showed that alterations in these genes can lead to defects and impaired heart function in zebrafish.

Finally, the researchers conducted experiments in various cell types in the laboratory to understand how the mechanism functions at the molecular level and what happens when the signaling pathways are disrupted.

The experiments, together with the genetic data from patients, pointed the researchers toward the mechanism in the primary cilium and thus to a possible explanation for the development of congenital heart defects.

"We investigate the mechanism from many different angles and using many different methods, all of which support what we observe in patients. Therefore, we are reasonably confident that this mechanism also exists in humans," says Lars Allan Larsen.

May be Crucial for Other Diseases

The researchers observed effects not only in the heart.

In the study, the rare genetic mutations were identified in patients with so-called syndromic Congenital Heart Disease. Syndromic heart defects are caused by an

"We have discovered a new communication system on the exterior of the cell that is crucial for the proper formation of the heart during embryonic development. This finding changes our understanding of how congenital heart defects arise. You could say that we have identified an important cog in a highly complex machine."

– Lars Allan Larsen
Expert in Congenital Heart Disease and Professor at the Department of Cellular and Molecular Medicine

underlying genetic syndrome that often also leads to defects and associated conditions in other organs.

At the same time, experiments in zebrafish and detailed studies of cilia in other tissues suggested that the mechanism is also important for the development of other organs.

"When the ciliary mechanism fails, it typically affects the development of several other organs as well. This may explain why some patients with Congenital Heart Disease also have defects and related conditions affecting the brain, kidneys and skeleton. The mechanism provides a unifying explanation for diseases that we have previously struggled to understand," says Søren Tvorup Christensen.

The researchers therefore believe that the discovery could help improve the understanding and treatment of a wide range of diseases caused by defects in the primary cilium.

"Many rare genetic diseases are caused by changes in genes that affect ciliary function, yet the underlying mechanisms have remained poorly understood. This new knowledge may eventually make it easier to identify patients early and develop targeted treatments," says Lars Allan Larsen.

Healthcare Barriers Impact Survival Rates for Adults With Congenital Heart Disease

American Heart Association

People with Congenital Heart Disease living in states with low household incomes and limited access to health insurance and the specialized care they need may be more likely to become disabled or die from Congenital Heart Disease, according to new, independent research published today in the Journal of the American Heart Association, an open-access, peer-reviewed journal of the American Heart Association.

Over the past 30 years, more children with Congenital Heart Disease have survived into adulthood due to better surgical and catheter-based treatments, as well as improvements in medical care. As these children grow into adults, they continue to require specialized cardiac care, as recommended by evidence-based American Heart Association/American College of Cardiology guidelines, to maintain lifelong health and well-being.

This is one of the first studies to examine the connection between the health and survival of adults with Congenital Heart Disease based on state-level data from the Global Burden of Disease Study along with income and insurance data from the U.S. Census, spanning from 1990 to 2021. Researchers examined the relationship among income levels, disability and death rates for nearly 300,000 adults with congenital heart disease aged 20 years and older.

What are the Key Findings of the Analysis?

- As median household income increased in a state, the death rate for people with Congenital Heart Disease decreased.
- The relationship between death rate and individual income levels was stronger than the connection between death rates and the percentage of residents without insurance in each state. This suggests that simply having health insurance did not guarantee that people accessed the specialized care required for Congenital Heart Disease. One reason for this might be differences in types of insurance coverage versus the overall presence of insurance.
- Geography and access to resources (namely, specialized cardiac care) likely play a profound role in death and disability in adults with Congenital Heart Disease in the US. More research is needed to understand these connections and their impact on the health, well-being and survival of people with Congenital Heart Disease.

"While having health insurance does matter, it does not explain the differences we found in terms of how long people with Congenital Heart Disease live," said Dr. Anitha John, MD, PhD, Senior Author, Medical Director of the Washington Adult Congenital Heart Program, Children's National in Washington, D.C. "This indicates that insurance alone doesn't guarantee access to care. People may still face barriers if their insurance does not cover specialized heart care or if out-of-pocket costs are too high. In many cases, specialized care may not be available in their area at all. We need to make sure everyone with Congenital Heart Disease has the same access to specialty care throughout their lifetime, regardless of where they live."

"We also need more trained specialists in adult congenital heart conditions. These medical experts should be more evenly distributed across the country, particularly where congenital heart disease patients live and work. Additionally, we need better systems to help patients get referred to the right care throughout their lives," she said. "Expanding telehealth and improving insurance networks may also help to improve access."

Michelle Gurvitz, MD, an American Heart Association volunteer expert and chair of the writing committee for the 2025 ACC / AHA / HRS / ISACHD / SCAI joint Guideline for the Management of Adults

"Understanding how social and economic factors can influence survival and outcomes is essential. Long-term outcomes and quality of life depend heavily on access to specialized, lifelong care for people with Congenital Heart Disease. Seeing how these factors affect patients long term allows us to better identify people at highest risk for complications. Then we can work toward improving access and reducing care gaps for people who have Congenital Heart Disease."

– Anitha John, MD, PhD

with Congenital Heart Disease, said, "The 2025 guideline outlines when to seek expert assistance and how specialists can work together with other healthcare providers to enhance access to care. Many patients stop receiving specialized care when they transition from pediatric to adult care. Additionally, this study shows that some patients cannot see specialists because of issues such as insurance or their location." Gurvitz, who was not involved in this study, is also a cardiologist at Boston Children's Hospital and an associate professor of pediatrics at Harvard Medical School.

According to the American Heart Association's 2026 Heart Disease and Stroke Statistics, congenital heart defects (heart or blood vessel issues that are present at birth) are one of the most common birth defects around the world. Congenital Heart Disease is the leading cause of death in the U.S. from a condition present since birth.

What are the Study Details, Background, Design and Limitations?

- Researchers reviewed data on death rates and "disability-adjusted life years" – the number of healthy life years lost due to a condition.
- Income levels, including household income and insurance status (considered uninsured if they lacked coverage for a full year), detailed by state were secured from the U.S. Census Bureau data.
- The findings show associations among the data points such as income, but cannot be interpreted as cause and effect. The associations found in the analysis may be influenced by factors like access to care, which the researchers could not directly measure.

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SEPTEMBER

18TH - 19TH

5th CME Cardiologists Conference
Athens, Greece
https://cardiologists.plenareno.com/

23RD - 24TH

2026 Facing Heterotaxy Together Annual Conference
Virtual
https://www.heterotaxy.org/latest/2026-facing-heterotaxy-together-virtual-conference

OCTOBER

19TH - 20TH

V Euro HeartCare & Cardiovascular Medicine Conference
Berlin, Germany
https://heart.plenareno.com/

NOVEMBER

13TH - 14TH

Transcatheter Pulmonary Valve Summit
Istanbul, Turkey

DECEMBER

03RD - 04TH

2026 International Aortic Symposium
Orlando, Florida, USA
https://floridaaorta.cme.ufl.edu/

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