



Table of Contents

1 Starting a Transition Program

*Jose Alfonso Silva Sepulveda, MD;
Howaida El-Said, MD, PhD;
Laith Alshawabkeh, MD, MSCI*

8 Pediatric Interventional Cardiology Coding Work Group Part Three: The Intra-Procedure and Post-Procedure Segments in a RUC Assessment of Total Procedural Time

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Jeff Delaney, MD, FSCAI;
Gurumurthy Hiremath, MD, FACC,
FSCAI;
Mark Hoyer, MD, FSCAI;
Frank Ing, MD, FACC, MSAI*

11 Medical News

- Help Improve The Understanding Of How Covid-19 Impacts CHD
- CorMatrix® Cardiovascular, Inc. Receives FDA Approval to Expand and Enroll 20 Additional Patients in the Adult Arm of its Early Feasibility IDE Study of the Cor® TRICUSPID ECM® Valve for Pediatric and Adult Patients
- Imaging Experts Publish New Guideline for Multimodality Assessment of Congenital Coronary Anomalies
- Dräger Supports Frontline Clinicians Battling COVID-19 Through Ventilator Training Alliance
- 2020 BSF Research Grant Program Awards

Starting a Transition Program

Jose Alfonso Silva Sepulveda, MD; Howaida El-Said, MD, PhD; Laith Alshawabkeh, MD, MSCI

Introduction

Congenital heart defects, also known as Congenital Heart Disease (CHD), result when the heart or blood vessels near the heart do not develop normally before birth. These defects are the most common types of birth defects, effecting 40,000 births per year in the United States.^{1,2} The advances in cardiac surgery, intensive care, and noninvasive diagnosis over the last 60 years have improved the survival rate for patients with CHD. It is now expected that at least 90% of babies born with CHD will reach adulthood.^{3,4} Since the year 2000, there are more adults than children living with CHD and this population is estimated to be growing at 5% per year.⁵ It is also estimated that more than 50% of these patients have moderately or severely complex CHD.^{3,4} As of 2010, there were approximately 2.4 million people (1.4 million adults, 1 million children) living with CHD in the United States.⁶ However, Mackie et al 2009⁷ reported that only 39% of patients with CHD between 18 and 22 years were receiving medical care in an outpatient cardiology setting. This practical limitation and the changes in demographics of patients with CHD has required the development of programs to ensure the smooth transfer of care from pediatric to adult health care settings, with the goal of continuing seamless care and preventing gaps in specialty care.

What is a Transition Program?

A transition program is a gradual process of preparing patients to take over the responsibility for management of their own health care needs. Transition is different than transfer of medical care. Transfer is moving patients and their care from a pediatric to an adult environment (which is eventually the goal), whereas transitional care allows patients to learn how to take charge of their health care. The goal of a transition program is to "provide uninterrupted health care that is patient-centered, age- and developmentally-appropriate, flexible, and comprehensive."⁸ In 2011, the AHA published guidelines for transition programs to include age-appropriate education about medical conditions and to promote skills in communication, decision making, self-care, and self-advocacy for patients.⁹ The transition process should begin at 12 years of age and should be the responsibility of all health professionals caring for patients with CHD. More important, the timing of starting transition education should be guided by the emotional maturity and developmental level of every patient.⁹ Transition education should be a gradual process toward "establishing autonomy, understanding one's cardiac anatomy and health status, and becoming aware of relevant lifestyle issues."¹⁰

Structure of a Transition Program

A transition care program should have a standard core educational curriculum that should be personalized to individual patient's needs (**Table 1**). Transition education should begin during routine clinic visits by a physician or a dedicated practitioner or educator¹¹ and should be the responsibility of everyone. In order to start a transition program, it is important to organize educational presentations to colleagues, parent groups, and hospital

TABLE OF CONTENTS

1 Starting a Transition Program

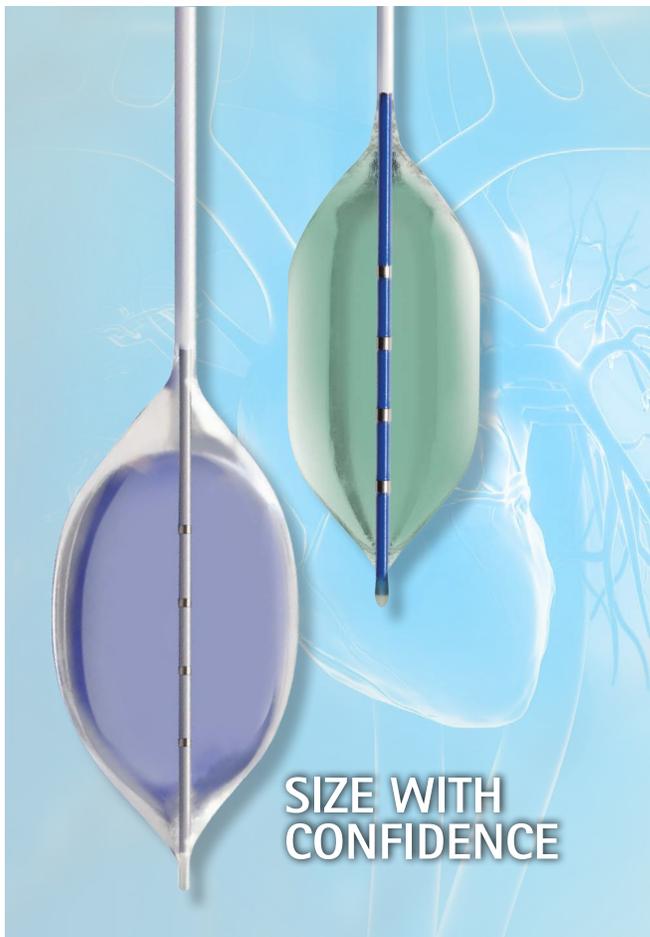
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administration in order to secure their commitment and support.⁸ Transition education can also be provided as a “class” outside of regular clinic hours.¹¹ In our institution, we have collaborated with the *Adult Congenital Heart Association* to start organizing patient/family-orientated quarterly meetings in public places to promote the transition education. The *Adult Congenital Heart Association* (<https://www.achaheart.org/>) is an organization dedicated to supporting families and individuals living with congenital heart disease by providing educational material, resources, and support, and organizing patient orientated conferences and seminars. An additional website, www.iheartchange.org, also provides information for patients and families related to CHD and transitional education.

Transition Clinic

The transition clinic is a dedicated clinic that is designed to address unique transitional issues and not to substitute general cardiac care from the primary pediatric cardiologist. Transition clinic visits provide a systemic and individualized approach to all patients to ensure that every patient receives a standard core educational curriculum (**Table 1**). These visits may be administered by a cardiologist, nurse educator or advanced practice nurse. In our institution, we have started a transitional clinic (<https://www.rchsd.org/programs-services/cardiology/services/transitional-program/>) that provides transitional/self-care assessments, additional resources and transitional education to both patients and families. The Rady Children's Hospital Transition Clinic has three dedicated visits for patients between 12-14 years of age, 15-17 years of age, and after 18 years of age to be able to address the typical developmental needs of every patient. Got Transition® (www.gottransition.org) has developed standardized transition/self-care assessment tools for pediatric and adult patients that have been adopted by the *American College of Cardiology* (<https://www.acponline.org/clinical-information/high-value-care/resources-for-clinicians/pediatric-to-adult-care-transitions-initiative/condition-specific-tools>).

In our institution, Dr. Huang¹² and her group have developed a Transition Electronic Health Record (EHR) Activity (TEA) tool that can be utilized in our EHR system (Epic). The TEA can track patients and provide a transition readiness self-assessment and specific resources/services on a scheduled basis (**Table 2**). The TEA is based on the [GotTransition.org](http://www.gottransition.org) transition assessment¹² and contains some minor modifications to encourage the use of MyChart application. MyChart (<https://www.mychart.com/>) is a web portal offered by most Epic healthcare organizations that provides patients access to their EHR with their mobile devices and computers. The TEA can also provide a practicum assessing knowledge of the heart condition and various transition readiness skills (**Table 3**). Patients receive specific resources and service information based on their individual assessment.

During the transitional care clinic visit, every patient receives an individualized medical record summary in the form of a medical passport. A medical passport (**Table 4**) provides essential clinical information specifically related to the clinical condition for providers and patients. This medical passport should be accessible to every patient on their MyChart accounts and mobile devices. It is important for a transitional care program to have a transition coordinator to function as a clinical expert, educator, and primary contact for transitioning patients, family members, and staff.⁸

Transfer

Transfer of “care from the pediatric to adult healthcare system occurs with the successful completion of a thoughtful transition process.”⁹ At our institution we promote a transfer policy for transferring patients to the adult healthcare system between 18 to 25 years of age. This is a flexible transfer policy that allows us to individualize the timing of the transfer based on “the developmental and psycho-social status” of every patient.⁹ For the transfer of a patient to occur, it is important to identify and collaborate with available Adult Congenital Heart Disease (ACHD) cardiologists that are able to take care of these patients. In our institution, we have developed a strong collaboration with our ACHD program at the University of California San Diego (<https://health.ucsd.edu/specialties/cardiovascular/programs/congenital-heart-disease/Pages/default.aspx>). It is critical to note that most general adult cardiologists are not well-prepared to take care of adults with CHD; the availability of an adult congenital cardiologist who is well-trained and board-certified in this specialty is essential. We ensure that every patient who is transferred to our institutional ACHD program receives an appointment and follow-up diagnostic tests scheduled in advance. EHR, surgical notes, procedures notes, and diagnostic images are available to the ACHD team prior to the first appointment of the patient. Finally, it is also important to continue with transition education once the patient is transferred to an adult healthcare system to assess any remaining gaps in self-care knowledge and skills or additional issues that need to be addressed.⁸ Every patient who establishes care with our ACHD program continues to receive transition education by the ACHD team. We have a monthly transition clinic located in UCSD, where the pediatric and ACHD providers both see select patients to enhance their transition experience. It is important to maintain constant communication between ACHD providers and pediatric providers to re-evaluate and coordinate transition strategies. We currently hold a weekly ACHD conference to discuss complex patients that involves the participation of both ACHD and pediatric providers. We have developed a model that allows smooth transition and transfer of care to an ACHD program without lapse in patient care. We have established a strong collaboration model in which both the pediatric and ACHD cardiologists, interventional cardiologists, electrophysiologists, and surgeons are involved in the care of adults with CHD throughout transition and after transfer of care.



TABLE 1 Transition Curriculum Topics^{9,11}

<p>Basic Knowledge of Congenital Heart Lesion</p> <ul style="list-style-type: none"> Name of lesion and previous interventions Medical therapy Residual hemodynamic issues Symptoms and how to respond Diagnostic tools in follow-up Understanding of frequency of follow-up Management options
<p>Non-Cardiac Issues</p> <ul style="list-style-type: none"> Follow-up with primary care physician Non-cardiac procedures/surgeries
<p>Lifestyle Habits and Exercise</p> <ul style="list-style-type: none"> Healthy eating Physical fitness Need for exercise limitations due to Congenital Heart Disease Weight control Avoidance of high-risk behaviors
<p>Career, Vocational, and Insurance Planning</p> <ul style="list-style-type: none"> Marriage and family planning Education Employment Life and health insurance
<p>Psycho-Social Issues</p> <ul style="list-style-type: none"> Anxiety and depression Self-care and self-advocacy Decision making
<p>Arrhythmia Concerns</p> <ul style="list-style-type: none"> Risks Signs and symptoms Screening tools Diagnostic tools Management options
<p>Endocarditis</p> <ul style="list-style-type: none"> Signs and symptoms Indications for antibiotics prophylaxis
<p>Females Only</p> <ul style="list-style-type: none"> Contraceptive options and risks Pregnancy risks Management of pregnancy plan Risk of transmission of congenital heart disease

TABLE 2 Transition Checklist

Transition checklist items by age

Patient answer options: Yes; No; I would like to know more

<p>12-14 years</p> <ul style="list-style-type: none"> ✓ I can describe my medical condition(s). ✓ I can name my medications and know what they are for and the amount and time I need to take them. ✓ I know my allergies to medications and medicines I should not take. ✓ I know my doctor's and nurses' names and roles. ✓ I can use and read a thermometer. ✓ I can ask and answer at least one question during my health care visit. ✓ I can manage my medical issues at school. ✓ I know my doctor's phone number and can call my doctor's office to make or change an appointment. ✓ Before my doctor's visit, I think about questions to ask. ✓ I have access to my own MyChart account and have checked MyChart.
<p>15-17 years</p> <ul style="list-style-type: none"> ✓ I know the names and purposes of the medical tests that are done. ✓ I know what can make my medical condition or health worse. ✓ I know my medical history. ✓ I answer most of the questions during a health care visit. ✓ I understand what drugs and alcohol do to my medical condition and health. ✓ I understand how my condition affects my sexuality and sex functions. ✓ I keep track of and keep my doctors' appointments. ✓ I know where to get medical care when my doctor's office is closed. ✓ I know how to fill out medical forms. ✓ I know how to refill my medications and who to contact regarding my medication refills (pharmacy or doctor's office). ✓ I carry important health information with me at all times (insurance card, allergies, medications, emergency contact info). ✓ I use MyChart to check my labs and medical reports.
<p>18+ years</p> <ul style="list-style-type: none"> ✓ My family and I have discussed my ability to make my own health care decisions at age 18. ✓ I understand how health care privacy changes at age 18. ✓ I have a plan so I can keep my health insurance after 18 or older. ✓ I have identified an adult physician for transfer of my care. ✓ I have made an appointment with an adult physician for transfer for medical care and am prepared for this appointment. ✓ I am aware of the resources available to me that I can use in regard to illness or disability. ✓ I know how to read a medical bill.



TABLE 3 Transition Practicum

Transition Practicum Questions

<p>1. The name of my heart condition is:</p> <p>2. My typical oxygen saturations are:</p> <ul style="list-style-type: none"> a. Less than 75% b. 75% to 85% c. 86% to 94% d. 95% to 100% <p>3. Please list your medications, dosages, and why you take each one:</p> <p>4. Please list the medications you are allergic to:</p> <p>5. Sometimes I need to take antibiotics when I see the dentist.</p> <ul style="list-style-type: none"> a. True b. False c. Unsure <p>6. The name of my cardiologist is:</p> <p>7. In terms of exercise, my cardiologist said I can:</p> <ul style="list-style-type: none"> a. Play any sport without restriction b. Should avoid contact sports but others are okay c. Gentle/easy exercise only d. Should not play any sports or do any exercise e. I don't know <p>8. It is 7 pm and you are not feeling well and feel like passing out, you should: (check all that apply)</p> <ul style="list-style-type: none"> a. Go the emergency room b. Sleep it off and wait until the morning c. Call you parents d. Call the hospital and ask for the cardiologist on call <p>9. I feel depressed, embarrassed, or anxious about my heart condition.</p> <ul style="list-style-type: none"> a. True b. False c. Unsure <p>10. My heart condition negatively affects my happiness.</p> <ul style="list-style-type: none"> a. Always b. Sometimes c. Unsure d. Rarely e. Never 	<p>11. Because of my heart condition, I have a higher risk of health problems from alcohol, cigarettes, and drugs.</p> <ul style="list-style-type: none"> a. True b. False c. I don't know <p>12. I will have to go to the cardiologist for the rest of my life (even if I feel healthy).</p> <ul style="list-style-type: none"> a. True b. False c. Unsure <p>13. I may need more surgeries/catheterization procedures in the future.</p> <ul style="list-style-type: none"> a. True b. False c. Unsure <p>14. My long-term career plans include: (check all that apply)</p> <ul style="list-style-type: none"> a. Work (immediately after high school) b. Community college c. Four-year college/university d. Graduate school/advanced degree <p>15. All types of contraception/birth control are safe for my heart (the pill, emergency contraception - the morning after pill, IUD, condoms, etc).</p> <ul style="list-style-type: none"> a. True b. False c. I don't know <p>16. I understand how pregnancy may affect my heart.</p> <ul style="list-style-type: none"> a. Yes b. Unsure c. No
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TABLE 4 Medical Passport

<p>Contact Information</p> <ul style="list-style-type: none"> Name of patient Cardiologist information Medical insurance information Pharmacy Medications/allergies Anticoagulation <p>Medications/Allergies</p> <ul style="list-style-type: none"> Anticoagulation 	<p>Cardiac Diagnosis</p> <ul style="list-style-type: none"> Cardiac diagram Cardiac diagnosis Surgical/Procedure History <p>Non-Cardiac Issues</p> <p>Emergency Care Plan</p> <ul style="list-style-type: none"> Typical oxygen saturations ECG image Pacemaker/ICD settings, company Artificial valve, INR goal 	<p>Studies</p> <ul style="list-style-type: none"> Last echo report Recent labs report <p>Indications for Antibiotics Prophylaxis</p> <p>Activity Restrictions</p>
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Pediatric Interventional Cardiology Coding Work Group Part Three: The Intra-Procedure and Post-Procedure Segments in a RUC Assessment of Total Procedural Time

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Abbreviations

AMA - American Medical Association
CCCHD - Cardiac Catheterization for Congenital Heart Disease
CMS - Centers for Medicare and Medicaid Services
CPT® - Current Procedural Terminology
PDA - Patent Ductus Arteriosus
PICCW - Pediatric Interventional Cardiology Coding Workgroup
RUC - Relative Value Scale Update Committee
RVU - Relative Value Units
TPVR - Transcatheter Pulmonary Valve Replacement

This is the third article in a series from the PICCW designed to educate providers on coding/billing practices for CCCHD, as well as update the community regarding ongoing projects. Importantly, the reader must understand these topics cover only one component of reimbursement, the physician work RVU. The other two components of the RVU system, practice expense RVU and professional liability RVU, are beyond the scope of this work.¹

Intra-Procedure Segment

Unlike the pre-procedure and post-procedure segments, the intra-procedure time is fairly straightforward and is generally thought of as the “skin-to-skin” time. In the congenital catheterization lab this begins with you/your surrogate placing hands on the patient, evaluating where to apply local anesthetic and begin the process of obtaining vascular access, including any ultrasound imaging. It concludes, very importantly, not with the sheath out time, rather with the time hemostasis is achieved and a dressing applied.

The most important concept to understand with estimation of intra-procedure time is that of capturing the “typical” scenario. The CPT®/RUC process generally defines “typical” as the scenario that is encountered in at least 51% of cases. Respondents to a RUC survey must read all of the information provided closely. There will be a vignette at the start of the survey, which will instruct as to what the typical patient is and ask whether the respondent agrees. It is important to bear in mind that the typical patient for each respondent may not necessarily be the same as the typical for the entire specialty. The survey respondent is supposed to be familiar with the procedure for the typical patient described, which may not necessarily be their typical patient. If they have no familiarity with a typical patient described, then they should not complete the survey.

For example, if a certain procedure is performed with two techniques for two distinct populations such as a PDA device closure, and takes 90 minutes for the standard technique, and 60 minutes in the newer technique, and the standard technique represents 51% or more of total cases, then the intra-procedure time should be reported as 90 minutes for the RUC survey, NOT the average time for the two techniques.

The concept of “typical” also applies to patients. If a procedure takes 60 minutes in patients under 5 years old and 30 minutes in patients over 5 years old, and 51% of cases are done in patients under 5 years, then the “typical patient” is under 5 years and the intra-procedure time should be reported as 60 minutes. On the spectrum of difficulty, if a typical case for a given procedure is quite simple the majority of the time, respondents should provide a time estimate for a representative, simple case using the standard technique. On the other hand, if the procedure is typically quite complex, such as a transcatheter pulmonary valve replacement (TPVR), then the time must account for and capture the work performed in a difficult case.

The CPT®/RUC process acknowledges that for any given procedure, the intra-procedure time varies from one patient to the next and from one operator to another. Inter-operator variation in intra-procedure time for a procedure is accounted for by surveying a large number of randomly selected operators. Inter-patient variation in intra-procedure time for a procedure (ie. shorter time in simple cases and longer time in complex cases) is accounted for by the respondent reporting the average time for the typical patient undergoing that specific procedure. In the above PDA example, where the “typical” case is done by the standard technique, the respondent considers all cases done by standard technique and provides an estimate of intra-procedure time for ONLY those cases, not the average time for all cases using both the standard and newer technique.

CMS also presumes every procedure has a typical learning curve, and over time, as experience is gained, work becomes easier and procedures take less time. Although this may be true for some specialties and some procedures, it has not necessarily been the case for complex congenital procedures. I will use as an example a TPVR. **Figure 1** depicts two bell shaped curves of intra-procedure time. The initial experience is represented by a typical curve with normal distribution. As with many new procedures, fairly straightforward patients are initially chosen to ensure procedure success and allow the provider to develop



comfort with the technique. If everything else remained constant, and provider experience was the only factor, it would be expected the curve would shift to the left, and average procedure times would decrease. In fact, what we typically experience is a shift to the right due to success causing a broadening of the procedural indications, and a willingness for providers to take on more difficult cases as their comfort level increases. Whereas the “typical” patient in the early days of TPVR was simple, the typical patient at present is much more complex. Since intra-procedure time for complex patients is longer, the curve has shifted to the right. This is also precisely why attempts to obtain data from registries such as IMPACT or CCISC are misleading, because such data averages the entire patient population undergoing the particular procedure, rather than the typical.

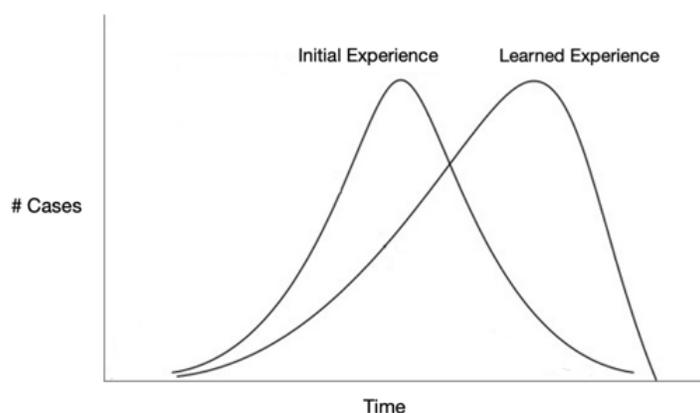


FIGURE 1 Change in intra-procedure time with increasing complexity exposure over time. The left-most curve reflects estimates of intra-procedure time by operators performing TPVR procedures on simple patients in the early experience. The right-most curve reflects estimates of operators performing TPVR in the larger number of more complex patients at the present time. **NOTE:** This figure is not based on any specific data set, rather only meant to be a figurative description of the effect of a change in patient population.

Post-Procedure Segment

The post-procedure time, similar to the pre-procedure, will include many tasks often performed by a physician surrogate (fellow, physician assistant, nurse practitioner, etc). These are nevertheless important tasks and typically add up to a considerable amount of time. Some of the typical items include:

1. A brief immediate post-procedure note
2. Medication reconciliation and post-procedure orders for nursing care
3. Patient accompanied to the recovery area and a verbal report given to the accepting team
4. Preparation of a detailed cardiac catheterization report, which includes: a diagram of the congenital heart defect, detailed description of the procedure performed, hemodynamic calculations and

interpretations of all data obtained, review and interpretation of the angiograms, and discussion of the findings and recommendations

5. All necessary data entered into the appropriate national data registry, as indicated/appropriate
6. A minimum of one physician bedside visit to assess the patient, including catheterization sites, discuss the findings with the patient and/or family, and review discharge instructions and follow-up information
7. Communicate the results to the referring provider

It is strongly recommended that, prior to taking a RUC survey, everyone watch the AMA’s tutorial video which can be found at the following link: <https://www.youtube.com/watch?v=cvMKO9tHhwQ>.

As you begin taking the survey, a list of comparative procedures will be presented from which you select the one most similar to the surveyed procedure. Often, these lists include many procedures with which you have no familiarity. Ideally, you will be able to find something that shares some similarity. If you are unfamiliar with the comparison procedures, you can refer to CMS’s published list of CPT® codes and related procedure times which can be found on their website at: <https://www.cms.gov/Medicare/Medicare-Fee-for-Service-Payment/PhysicianFeeSched/PFS-Federal-Regulation-Notices-Items/CMS-1715-F>.

After all, it is impossible to accurately state whether the surveyed procedure is similar in time compared to a procedure with which you are unfamiliar. The next series of questions will compare the reference procedure selected to the one being surveyed in terms of the intensity and skill required. A final question asks you to estimate the physician work RVUs that should be assigned to the service being surveyed. Your estimate should be based on your estimates of the collective time required (including pre-, intra-, and post-time) and the intensity of the service in comparison to other services with established RVU values.

In Part Two of this series, we discussed the failure to place appropriate priority and attention to completing the surveys. We repeat this once again. It is imperative for all providers to respond in order to capture the great variability in practice across the country. Of the roughly 150 US centers providing congenital cardiac catheterization services, only 62 have a general pediatric cardiology fellowship program. This contributes greatly to the variability in available resources and staff from institution to institution.² No single provider should assume the work they perform is the same elsewhere. In fact, the only way to ensure your work is captured and represented fairly is to complete the survey. The importance of providers having an understanding of this process and remaining engaged cannot be understated. Otherwise, it will continue to undermine the community as a whole and the PICCW’s efforts to correct these longstanding deficiencies in the fair and proper acknowledgment of the work we do.



In the next article, we will discuss other obstacles beyond physician education and involvement, which have contributed to the problems our community faces.

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2. <https://freida.ama-assn.org/Freida/#/programs?specialtiesToSearch=325>



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CorMatrix® Cardiovascular, Inc. Receives FDA Approval to Expand and Enroll 20 Additional Patients in the Adult Arm of its Early Feasibility IDE Study of the Cor® TRICUSPID ECM® Valve for Pediatric and Adult Patients

PRNewswire - CorMatrix® Cardiovascular, Inc. www.cormatrix.com, a leading developer of regenerative cardiovascular medical devices, announced receiving FDA approval to expand and enroll 20 additional patients in the adult arm, including up to four additional cardiac surgery research and investigative centers, for its early feasibility IDE study of the Cor® TRICUSPID ECM® valve* for pediatric and adult patients. The Cor® TRICUSPID ECM® valve has been successfully implanted in the 11th patient enrolled in the expansion by Dr. Marc Gerdisch, Chief of Cardiothoracic Surgery at Franciscan Health Heart Center in Indianapolis, Indiana and principal investigator for the adult component of the study. The Cor® TRICUSPID ECM® valve is a next generation, first of its kind, biologic, seamless, and stentless cardiac valve composed of extracellular matrix or ECM®.

"The most recent implant of the CorMatrix Cor® TRICUSPID valve represents an important step toward realizing an implantable, regenerating tissue-engineered heart valve. We are now broadening the study to additional centers which will greatly increase our enrollment. So far the valves are performing very well, and patients are excited to be part of this important innovation," said Dr. Marc W Gerdisch, Chief of Cardiothoracic Surgery at Franciscan Health Heart Center in Indianapolis, Indiana & principal investigator for the adult component of the CorMatrix® Cor® TRICUSPID IDE safety and feasibility clinical trial.

"CorMatrix® is very excited to expand enrollment of the adult arm of its FDA early feasibility IDE study for the Cor® TRICUSPID ECM® valve. This is just one step closer to ultimately providing biologic valve technology to an ever-expanding patient need. The Cor® TRICUSPID ECM® valve is the first of its kind that provides a new treatment option. As a result, we are very pleased to receive the approval from the FDA to expand the number of study patients and centers," said Edgar Rey, President and CEO, CorMatrix® Cardiovascular, Inc.

CorMatrix® Cardiovascular, Inc. is a regenerative biotechnology company based in metro Atlanta, Georgia. A pioneer and leader in regenerative science and technology, the company was founded to address congestive heart failure, the largest global disease management challenge and unmet cardiovascular clinical need. CorMatrix® provides regenerative, technological innovations, and patient solutions for the treatment of congestive heart failure and other cardiovascular diseases. The company is committed to developing innovative future non-synthetic, regenerative devices for the cardiovascular system through continued research and improvements to the CorMatrix® ECM® technology.

*Cor® TRICUSPID ECM® valve is an investigational device and not commercially available.

For more information, please contact Edgar Rey, President and CEO at erey@cormatrix.com or visit www.cormatrix.com



Help Improve the Understanding of How Covid-19 Impacts CHD

Patients and families want to know how COVID-19 could affect their child or themselves. Right now, we don't know. But you can help.

If you or your child have CHD and have symptoms or tested positive for COVID-19, we are asking you to complete a short survey. This study is unique because it collects information directly from people with CHD, of all ages and all types of CHD. Other research that looks at hospital records only identifies those who have become so ill they seek medical treatment as a result of COVID-19. With your help, we can reach adults and children with CHD from across the country with mild, moderate and severe responses to COVID-19, to provide a more complete picture of the impact of COVID-19 on people with CHD.

Information from this survey will not answer everyone's questions about CHD and COVID-19, but it will help us begin to gather, analyze and disseminate information specific to the congenital heart community, both now and in the future.





CHD and COVID-19
Help us learn more.

Complete this brief survey today!
conqueringchd.org/InformCHD



INFORMCHD
A PROGRAM OF Conquering CHD



Imaging Experts Publish New Guideline for Multimodality Assessment of Congenital Coronary Anomalies

Experts in the medical imaging community have developed a landmark consensus document to optimize care of patients with congenital coronary anomalies. These defects of the blood vessels that supply blood to the heart muscle can be an important cause of a heart attack and sudden cardiac death in children and young adults, but historically they have been difficult to identify without cardiac catheterization. However, recent advances in multimodality imaging techniques have demonstrated increasing utility in the characterization of most congenital coronary anomalies in all age groups, and these techniques can complement or reduce the need for invasive angiography in many cases. Recommendations for Multimodality Assessment of Congenital Coronary Anomalies: A Guide from the American Society of Echocardiography (ASE), https://www.asecho.org/wp-content/uploads/2020/03/ConCoronary_March2020.pdf, provides guidelines for optimization of imaging for congenital coronary anomalies, with a review of the benefits and limitations of the different imaging techniques, including echocardiography, cardiac computed tomography, cardiac magnetic resonance imaging, nuclear myocardial perfusion imaging, and angiography. This guideline was developed in collaboration with the Society for Cardiovascular Angiography and Interventions, the Japanese Society of Echocardiography, and the Society for Cardiovascular Magnetic Resonance, and has also been endorsed by 17 ASE International Alliance Partners.

ASE's Chair of the writing group, Peter Frommelt, MD, FASE, of Children's Hospital of Wisconsin and the Medical College of Wisconsin in Milwaukee said, "Congenital coronary artery anomalies, both in isolation and associated with other forms of Congenital Heart Disease, have been recognized as having significant potential morbidity and mortality, including sudden cardiac death in children and adolescents. This document outlines specific strategies for imaging of each of the known congenital coronary anomalies, providing cardiac imaging specialists with a valuable resource to improve patient care and foster responsible utilization of diagnostic imaging modalities".

In conjunction with the publication of this guideline, Dr. Frommelt will conduct a live webinar, including a question and answer section, on Tuesday, April 28, 2020, at 1:00 PM Eastern time. The webinar will be available for free to all ASE members and open to all other clinicians for just \$25. Registration and access to all ASE-hosted guideline webinars is available on <https://aseuniversity.org/ase/>.

The full guideline document is available on the *Journal of American Society of Echocardiography* (JASE) website, <https://www.onlinejase.com/>. This document and all ASE Guideline documents are also available to the medical community at <https://www.asecho.org/guidelines-search/>.



Dräger Supports Frontline Clinicians Battling COVID-19 Through Ventilator Training Alliance

Centralized Repository of Ventilator Training Resources Accessed Through a Mobile App Connects Clinicians With Critical Information at the Point of Patient Care

Recognizing the essential role of ventilators in the treatment of COVID-19 patients, and the need for frontline healthcare providers to receive training on this critical equipment asset, Dräger has joined forces with other global ventilator manufacturers to form a Ventilator Training Alliance (VTA).

"At Dräger we are doing everything in our power to support healthcare professionals on the frontlines of the COVID-19 pandemic," said President and CEO for Dräger in North America, Lothar Thielen. "Healthcare professionals treating patients suffering from COVID-19-related respiratory distress are faced with making life-saving decisions regarding ventilation strategies every day. Through our participation in the VTA, Dräger is working collaboratively with other ventilator manufacturers to provide clinicians quick access to the resources they need to save lives."

Dräger, GE Healthcare, Getinge, Hamilton Medical, Medtronic, Nihon Kohden and Philips have formed this humanitarian training coalition, and partnered with learning and readiness platform provider Allego to create a mobile app that frontline medical providers can use to access a centralized repository of ventilator training resources. As area hospitals share resources on various ventilator models, the need for the VTA app to provide quick technical guidance becomes of paramount importance during the pandemic crisis.

The VTA app – powered by Allego – connects respiratory therapists, nurses and other medical professionals with ventilator training resources from alliance member companies, including instructional how-to videos, quick reference guides, and contact information to ICON (Intensive Care On-line Network) for 24x7 clinical support critical to helping clinicians treat patients suffering from COVID-19-related respiratory distress.

How to Access the Ventilator Training Alliance Hub

The app is provided at no cost to medical professionals. To download the Ventilator Training Alliance knowledge hub application, visit the **Apple App Store** or **Google Play Store**, or visit <https://vta.allego.com/index.do> to access the hub from any Web browser.

Dräger. Technology for Life®

Dräger is an international leader in the fields of medical and safety technology. Our products protect, support, and save lives. Founded in 1889, Dräger generated revenues of almost EUR 2.8 billion in 2019. The Dräger Group is currently present in over 190 countries and has more than 14,500 employees worldwide. Please visit www.draeger.com for more information.





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- This event will also include a Nightmare Case Session, a top 20 Oral Abstract Session, and Interaction with Exhibitors.
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2020 BSF Research Grant Program Awards

The goal of the BSF Research Program is to foster the discovery and development of therapies to alleviate suffering and prolong life for individuals affected by Barth Syndrome.

To that end, the 2020 research grant recipients demonstrated innovative and scientifically rigorous approaches to addressing knowledge gaps in two key areas: Barth discovery science and development of therapeutic opportunities.

Since 2002, the Barth Syndrome Foundation Research Grant Program has awarded a total of US \$5.1 million via 115 research grants to 68 principle investigators worldwide in order to better understand this rare X-linked genetic disease characterized by cardiomyopathy, growth delay, muscle hypoplasia, neutropenia and extreme fatigue.

In consultation with BSF's Scientific and Medical Advisory Board, and with the support of the international affiliates - Barth Syndrome Foundation of Canada, Barth Syndrome UK, Association Syndrome de Barth France, and Barth Italia Onlus - our strategic seed-funding approach has resulted in BSF's original research investments translating into US \$30.7 million in follow-on funding for Barth syndrome research and clinical product development.

For the 2020 grant cycle, which opened in summer of 2019, BSF received 15 competitive applications to study discovery science and therapeutic opportunities of Barth syndrome. Guided by our SMAB reviewers and outside experts, BSF is proud to announce the funding of four projects that will continue our efforts to advance research and treatments for Barth syndrome.

Investigation of a New Nutraceutical for Treatment of Barth Syndrome

Robin E. Duncan, PhD, Associate Professor
University of Waterloo, Waterloo, ON, Canada
Award - \$41,580 over 2-year period

This project will assess the therapeutic potential and activity of a nutraceutical (a possible supplement therapy that is available without prescription) in preserving the viability of Barth syndrome cells. Following up on early results that this nutraceutical has the ability to help Barth syndrome cells survive at the same levels as normal cells, Dr. Duncan and her team will try to understand what is the process that helps preserve these cells, and further expand her research into the Taz knockout (TAZKO) mouse model. As an early stage research effort (aka preclinical study), this research aims to provide the foundational understanding of this nutraceutical and its impact on Barth syndrome. This project's funding was made possible by generous contributions from our affiliates Barth Syndrome Foundation of Canada and the Barth Syndrome UK.

Structural and Biophysical Studies of Tafazzin

Steven Glynn, Associate Professor
Stony Brook University, Stony Brook, NY
Award - \$50,000 over 2-year period

Tafazzin catalyzes the transfer of unsaturated acyl chains to generate mature cardiolipin at the mitochondrial inner membrane. Mature cardiolipin is essential for the proper organization and function of the inner membrane and reduction in cardiolipin level impairs cristae formation and energy production. At least 50 missense mutations in Tafazzin have been identified in patients with Barth syndrome (BTHS), an X-linked disease characterized by multiple myopathies and cyclic neutropenia. These mutations impair Tafazzin activity, resulting in reduced cardiolipin levels and accumulation of phospholipid precursors. Thus, the activity of Tafazzin appears to be inextricably linked to the development of Barth syndrome in patients. In this proposal, we seek to determine the atomic resolution structure of yeast Tafazzin to provide the first structural insights into this enzyme from any species.

Thirty-six of the fifty BTHS patient mutations in human Tafazzin are located at identical or highly similar positions in the yeast enzyme making it an excellent model to study the molecular basis of this disease. This structure will reveal the mechanisms of specificity and catalysis of cardiolipin maturation at the inner membrane and provide a structural framework for rationalizing impaired Tafazzin activity caused by BTHS patient mutations. Furthermore, we will use biophysical methods to probe defects in Tafazzin stability caused by one class of BTHS mutations that have been shown to induce its degradation by an intermembrane space protease. Together, these studies will shed light on the molecular mechanisms of BTHS mutations within Tafazzin and demonstrate a key hypothesis to understand how one class of mutation can lead to disease.

Cardiolipin Requirement for Mitochondrial Calcium Import

Vishal Gohil, PhD, Associate Professor
Texas A&M University, College Station, TX

The clinical abnormalities observed in Barth syndrome patients are caused by perturbations in mitochondria, the powerhouse of the cell. These perturbations have been traced to defects in the biosynthesis of cardiolipin, a building block of the mitochondrial membranes. Although decades of research have identified critical roles of cardiolipin in different mitochondrial functions, we still do not know the full spectrum of cardiolipin-dependent mitochondrial functions that may contribute to Barth syndrome disease pathology. One important factor that controls mitochondrial energy production is calcium signaling. Because mitochondrial calcium import machinery is



localized to mitochondrial membrane, we reasoned that cardiolipin deficiency might disrupt calcium import. Indeed, our preliminary results show that the abundance and activity of mitochondrial calcium uniporter, a highly selective calcium channel, is decreased in cellular models of Barth syndrome. This key finding forms the basis of our hypothesis that depletion of cardiolipin levels could impair mitochondrial calcium signaling. We will test this hypothesis by determining whether calcium-signaling dependent mitochondrial bioenergetics is perturbed in Barth syndrome patient cells and heart tissue. These studies will uncover the role of mitochondrial calcium signaling in Barth syndrome disease pathology, which will provide a new way to understand and treat this debilitating disease.

Essential Activities of Tafazzin that are Independent of Cardiolipin Remodeling

William T. Pu, MD, Professor
Boston Children's Hospital, Boston, MA
Award - \$50,000 over 1-year period

Barth syndrome is caused by mutation of Tafazzin (TAZ), an enzyme needed to properly produce cardiolipin, an essential component of mitochondria. Mitochondria are needed in all cells, especially muscle cells, for metabolism and energy production. In Barth Syndrome mice, most mice die during the neonatal period. Gene therapy with a virus that replaces the mutant TAZ with normal TAZ prevented neonatal death and allowed most mice to live to adulthood. Unexpectedly, replacement of mutant TAZ with naturally occurring forms of TAZ that are unable to produce cardiolipin ("variant TAZ") still rescued some Barth mice from neonatal death. This suggests that TAZ has additional functions beyond its ability to produce cardiolipin. We hypothesize that these additional functions are due to TAZ protein interacting with other proteins. Here we will measure mitochondrial activity of Barth cells treated with normal or variant TAZ. We will identify other proteins that interact with normal and variant TAZ. These studies will allow us to discover TAZ activities that are independent of its ability to make cardiolipin.





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