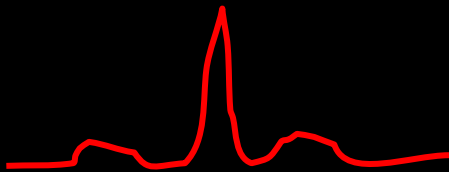


# Adult Congenital Heart Disease

Improving Education and Communication  
Among Cardiologist



Curt J Daniels, MD, FACC

Professor, Internal Medicine and Pediatrics

Director, **COACH** Program **C**olumbus **O**hio **A**dult **C**ongenital **H**ear Disease and  
Pulmonary Hypertension Programs

Division of Cardiology, The Ohio State University & The Heart Center at Nationwide  
Children's Hospital



# PATCH Program

## Provider Action for Treating Congenital Hearts





## **ACC Chapters Unite with the Adult Congenital Heart Association to Improve the Care for ACHD Patients:**

### *Provider Action for Treating Congenital Hearts (PATCH) Pilot Program Chapter Opportunities*

#### **The ACC/ACHA Provider Action for Treating Congenital Hearts (PATCH) Program:**

ACHA and ACC are working to collaborate on the PATCH Program to address four major challenges to the provision of high quality coordinated ACHD care in the U.S.:

- **Lack of educational resources specific to the complex needs of the ACHD population**
- **Lack of awareness of ACHD care guidelines**
- **Lack of networking between ACHD specialists and general cardiologists**
- **Need for greater access to ACHD trained cardiologists and centers of excellence**





# CHD POPULATION

# CHD - Population

---

- 40,000 infants born with CHD/ year.
- THE most common birth defect
- What is successful outcome?
  - Surviving initial surgical repair
  - Surviving to 1 year of age
  - Normal childhood
  - Normal adolescence

**Surviving to Adulthood**



# ACHD - Population

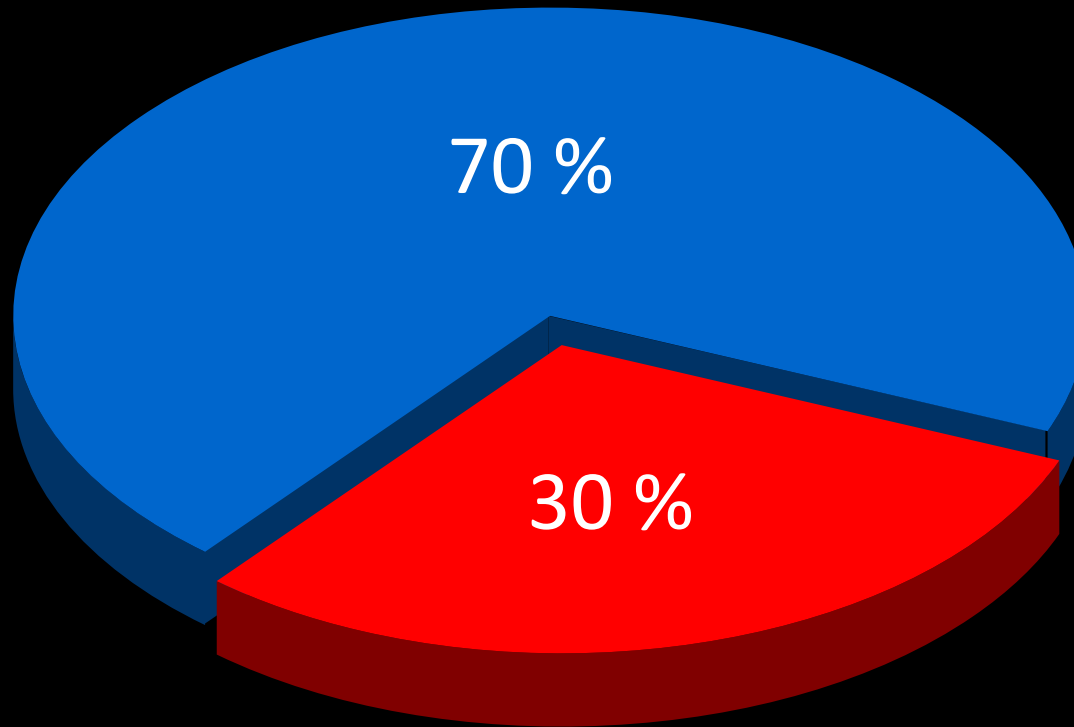
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**Surviving to  
Adulthood is Now  
Expected**

# Congenital Heart Disease Population

---

 PEDIATRIC  
 ADULT

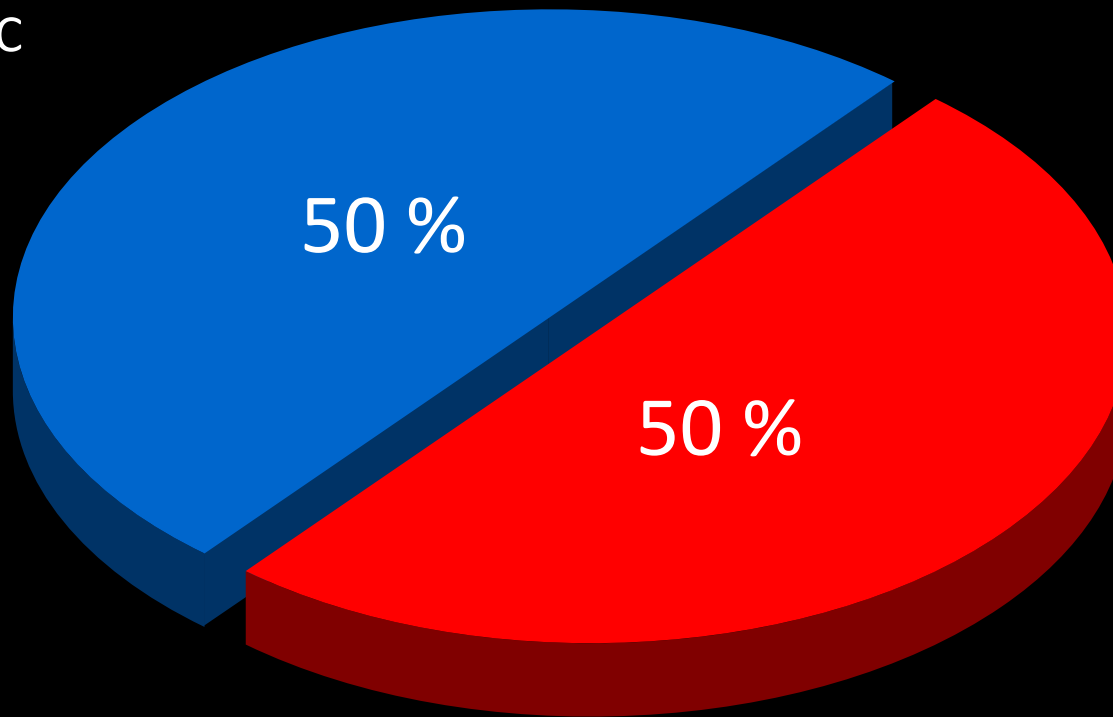


1965

# Congenital Heart Disease Population

---

 PEDIATRIC  
 ADULT

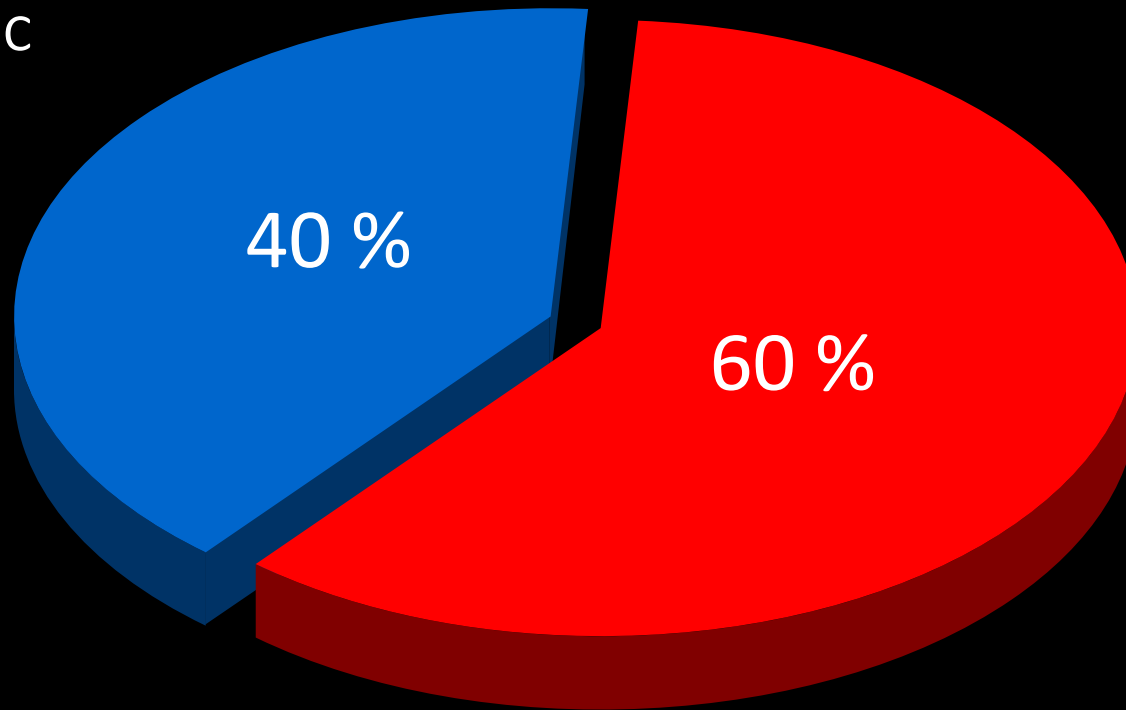


2000

# Congenital Heart Disease Population

---

 PEDIATRIC  
 ADULT



2010

# Adult vs Pediatric Complex CHD Populations in Canada

- Single Ventricle
- Pulmonary Atresia
- Transposition Complexes
- Eisenmenger syndrome
- Cyanotic CHD

■ Adults  
■ Children

Complex CHD

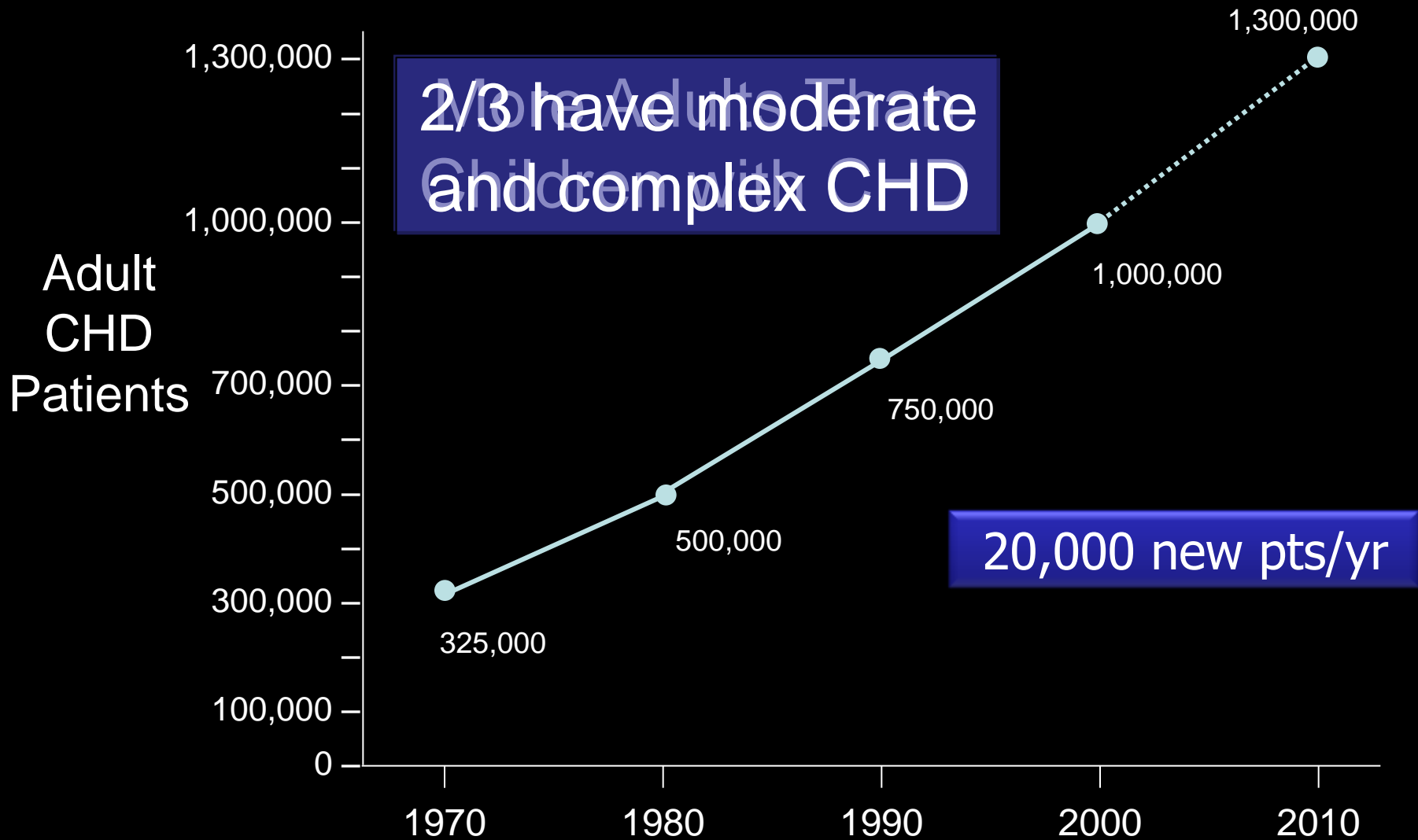


The Prevalence of SEVERE CHD has Increased 85% for Adults vs 22% for Children

Percent

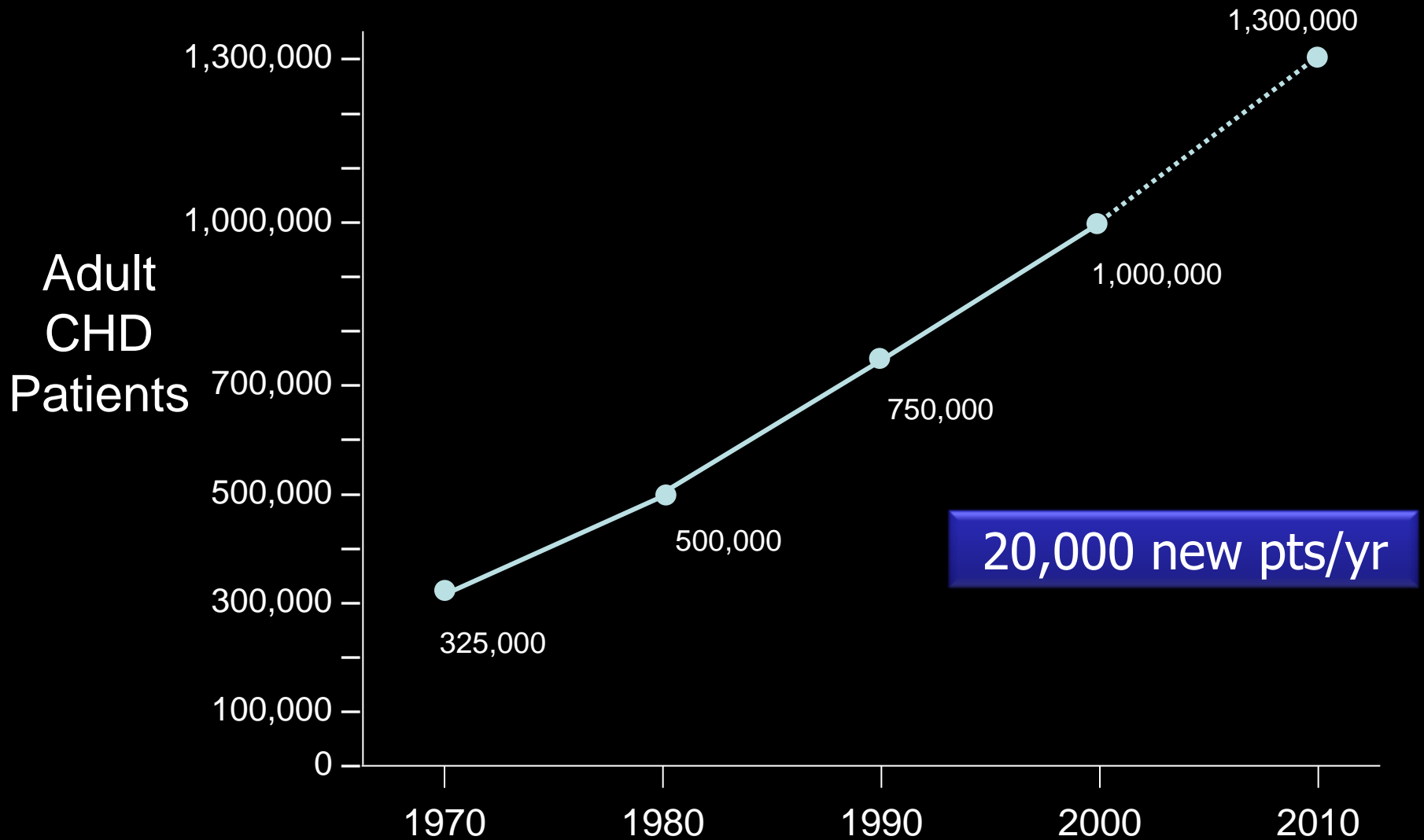
Number Alive

# Patients Reaching Adulthood with CHD

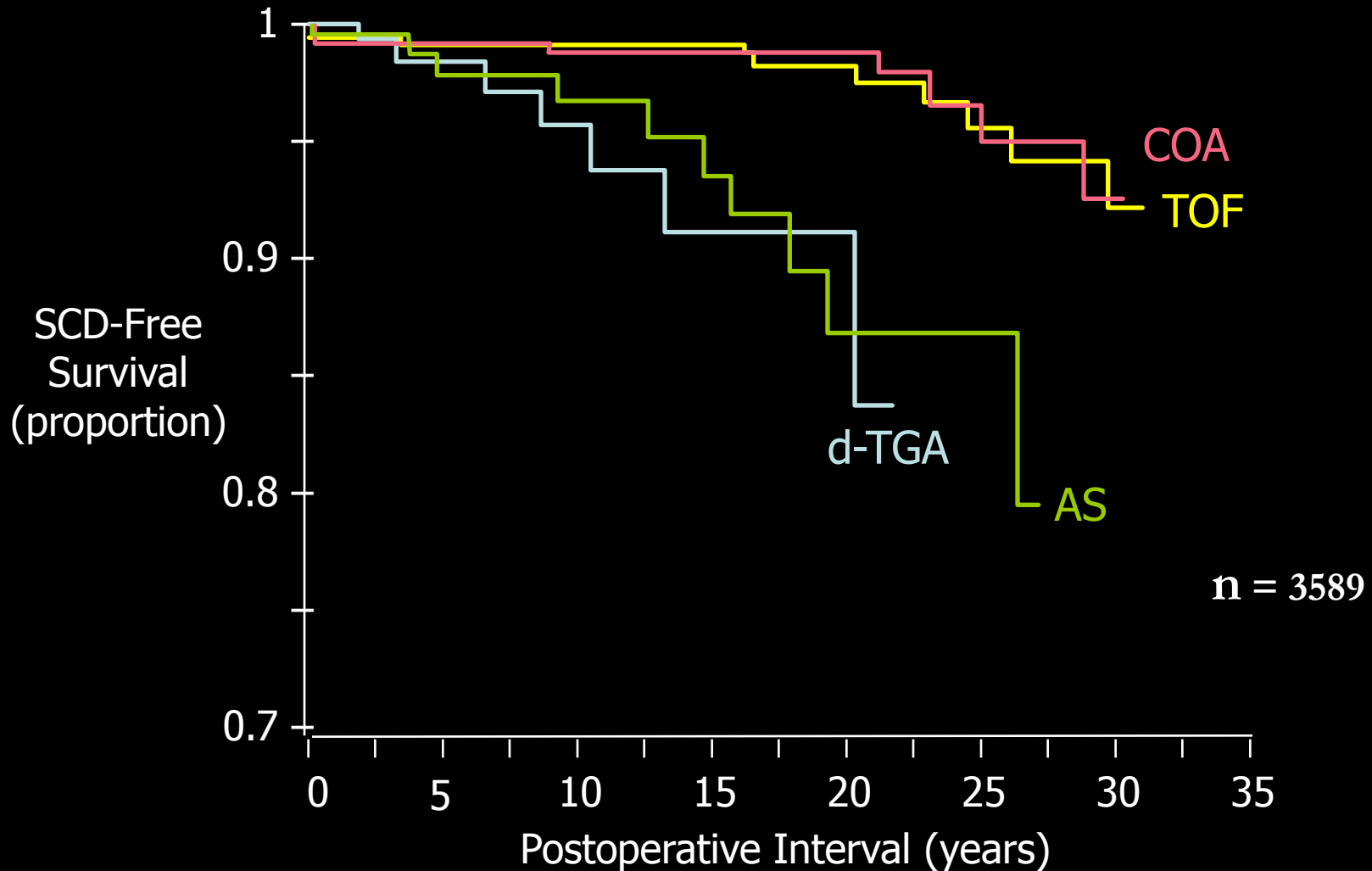


**PROBLEM**

# Patients **Reaching** Adulthood with CHD



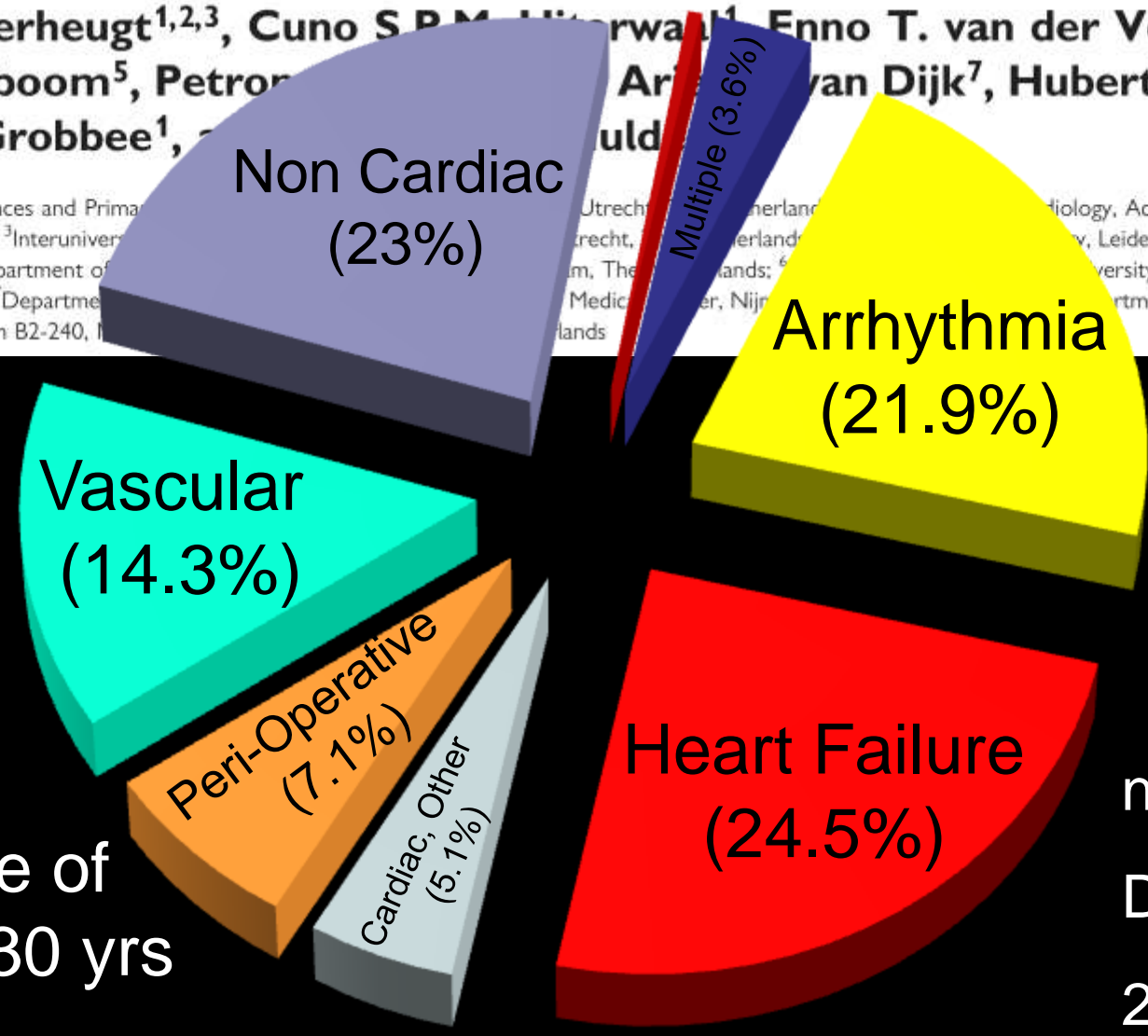
# Actuarial Probability of SCD-Free Survival After Surgical Treatment



# Mortality in adult congenital heart disease

Carianne L. Verheugt<sup>1,2,3</sup>, Cuno S.P.M. Hitterwaal<sup>1</sup>, Enno T. van der Velde<sup>4</sup>,  
Folkert J. Meijboom<sup>5</sup>, Petronella A.M. van Dijk<sup>7</sup>, Hubert W. Vliegen<sup>4</sup>,  
Diederick E. Grobbee<sup>1</sup>, ...

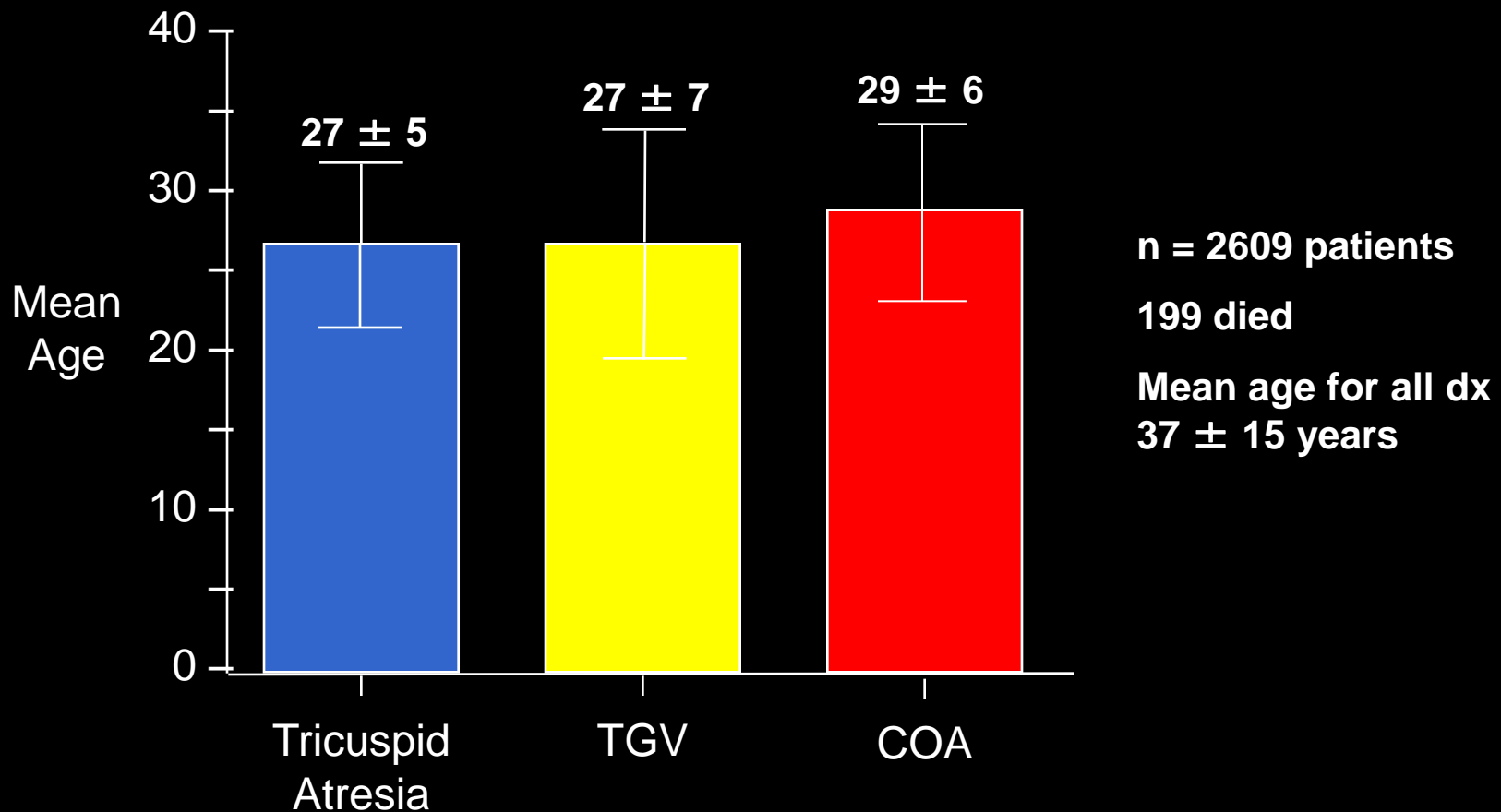
<sup>1</sup>Julius Center for Health Sciences and Primary Care, University Medical Center Utrecht, Utrecht, The Netherlands; <sup>2</sup>Interuniversity Institute for Health Economics Research, University Medical Center Groningen, Groningen, The Netherlands; <sup>3</sup>Department of Cardiology, University Medical Center Groningen, Groningen, The Netherlands; <sup>4</sup>Department of Cardiology, University Medical Center Groningen, Groningen, The Netherlands; <sup>5</sup>Department of Cardiology, University Medical Center Groningen, Groningen, The Netherlands; <sup>6</sup>Department of Cardiology, University Medical Center Groningen, Groningen, The Netherlands; <sup>7</sup>Department of Cardiology, University Medical Center Groningen, Groningen, The Netherlands



Mean Age of Death < 30 yrs

n = 6,933  
Died 197  
24,865 pt yrs

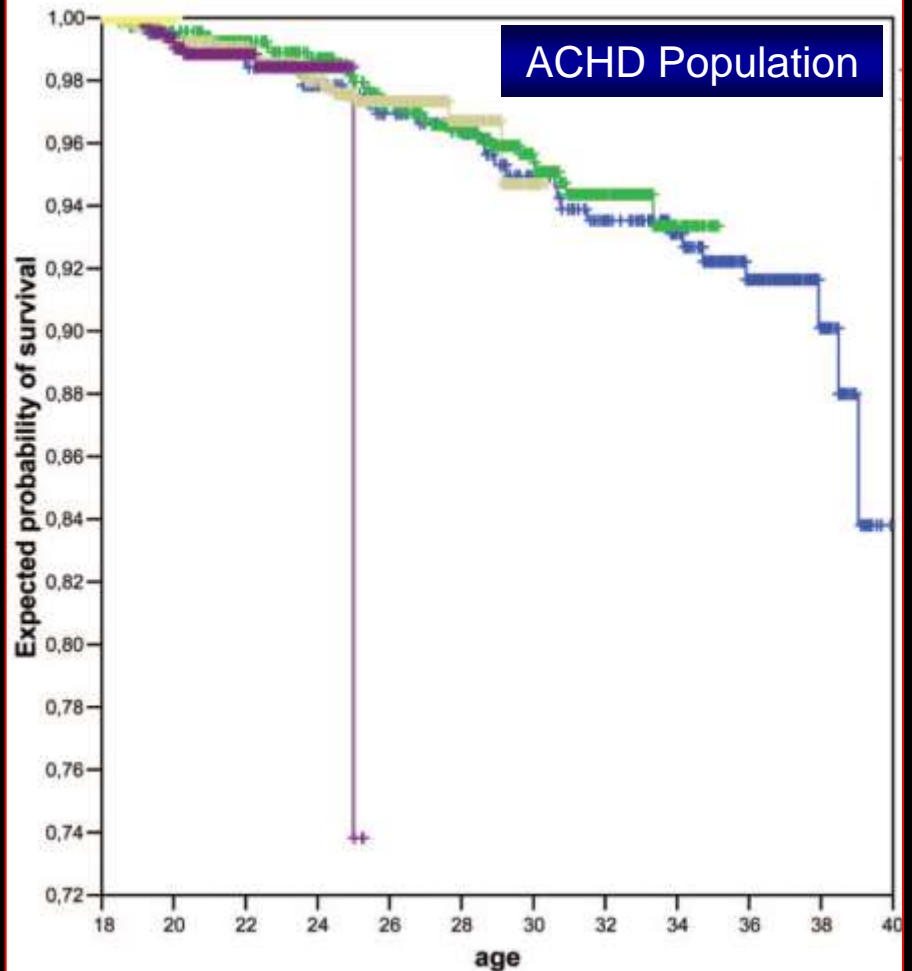
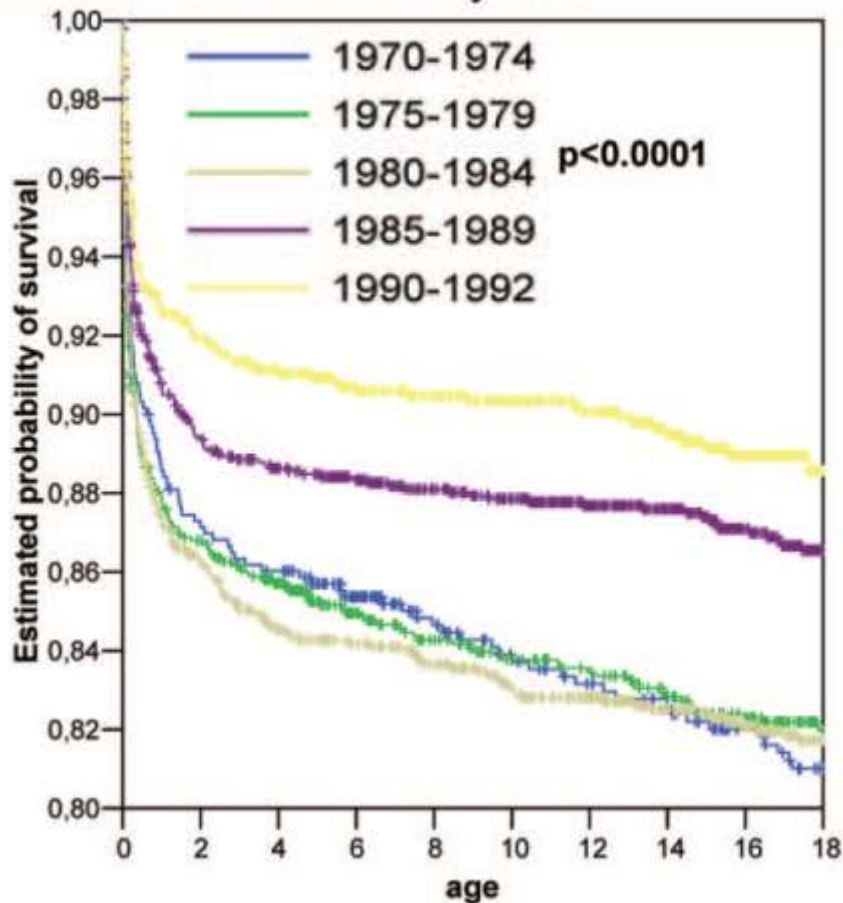
# Age at Death for Adults with CHD



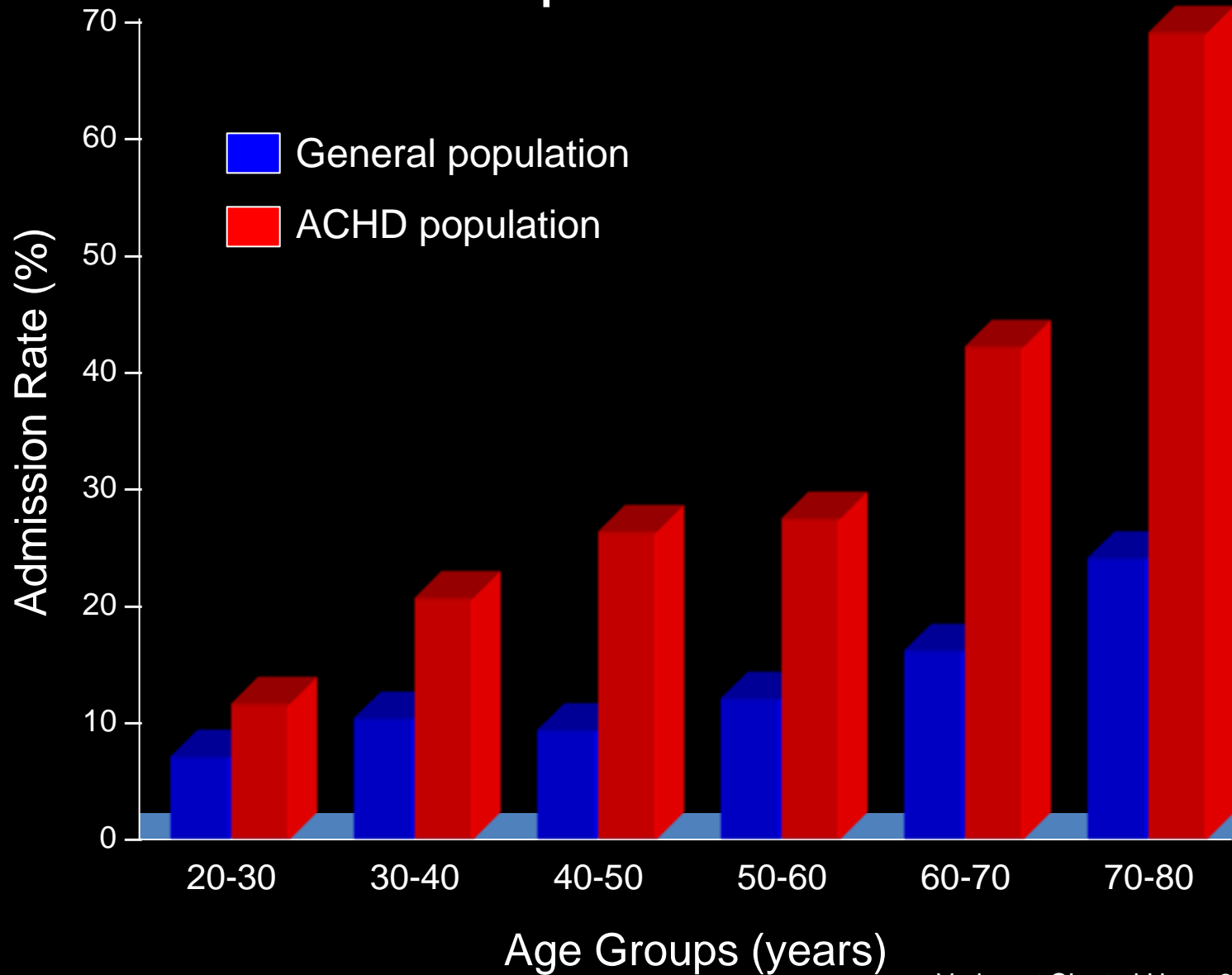
# Temporal Trends in Survival to Adulthood Among Patients Born With Congenital Heart Disease From 1970 to 1992 in Belgium

Philip Moons, PhD, RN; Lore Bovijn, MSc, RN; Werner Budts, MD, PhD;  
Ann Belmans, MSc; Marc Gewillig, MD, PhD

### Survival from birth to 18 years

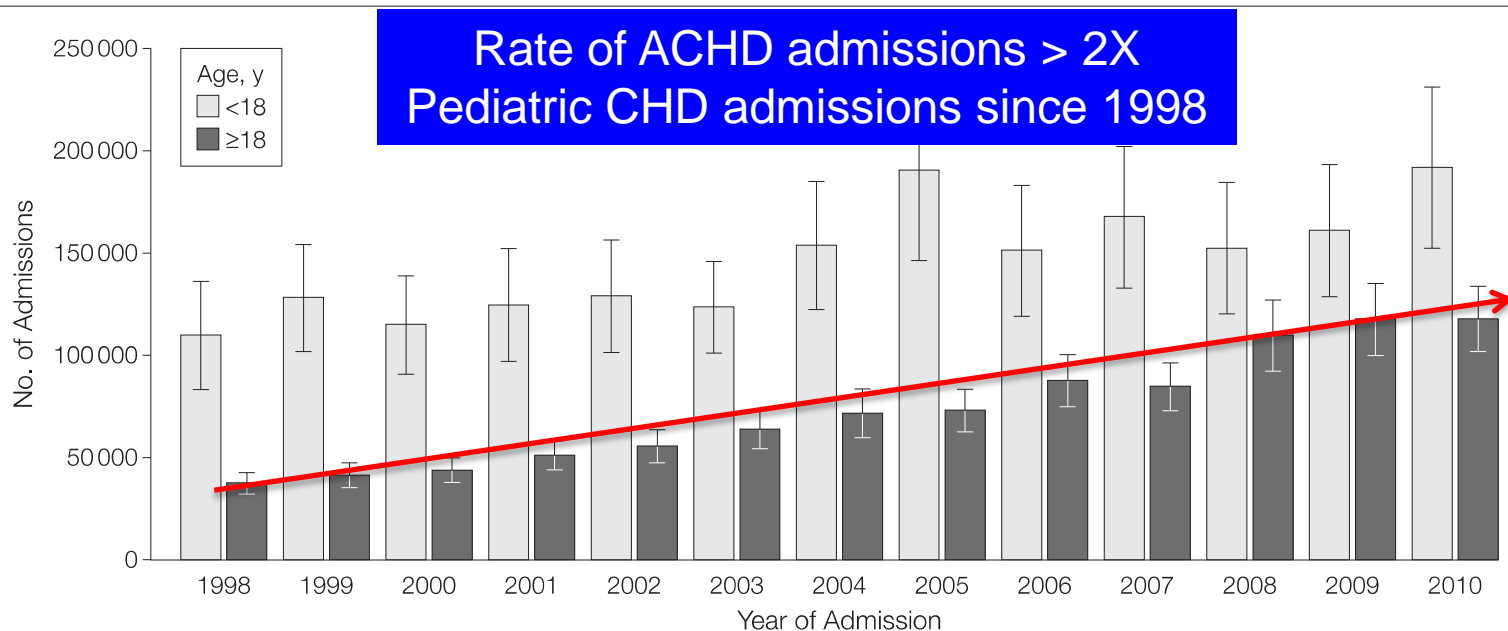


# Hospital Admission Rate General Population vs ACHD



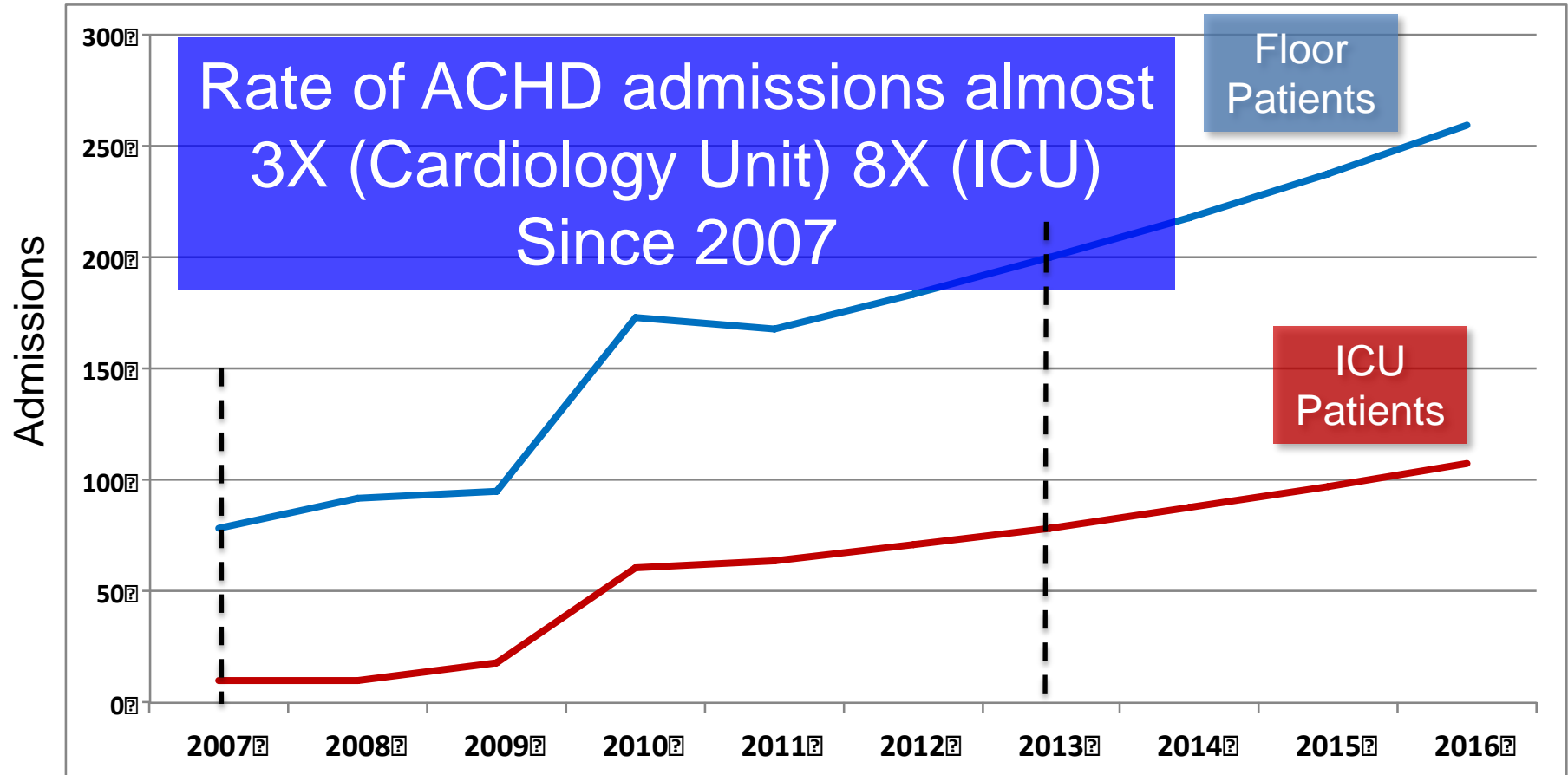
# MORBIDITY

**Figure.** Annual Pediatric and Adult Congenital Heart Disease Admissions in the United States



Error bars represent 95% CIs.

# COACH ACHD Inpatient Projections



# Patients **Reaching** Adulthood with CHD

## Once Reaching ACHD

- **Survival is not as expected**
- **HF and arrhythmia (~45%)**
- **Morbidity is substantial**



# Long –Term Complications

---

## Adult Co-Morbidities

- Atrial
- Ventricular
- Sudden Death
- CAD, PVD
- DM
- OSA, COPD
- Renal and Hepatic Insufficiency
- Right Heart Failure
- Left Heart Failure
  - Systolic
  - Diastolic
- Pulmonary Hypertensi
- Residual Shunts
- Valvular Disease



**38 yo with TOF s/p  
repair, DM, presents  
with chest pain**



Heart Failure

Acquired Heart Disease

Pulmonary Hypertension

Arrhythmias

Liver Disease

**ACHD**

Re-operation

Aortic Disease

Valve Disease

Vascular Disease

High Risk Pregnancy

PEDIATRIC EP

HF/TXPL

PEDIATRIC CARDIOLOGY

INTERNAL MEDICINE CARDIOLOGY

INTERNAL MEDICINE EP

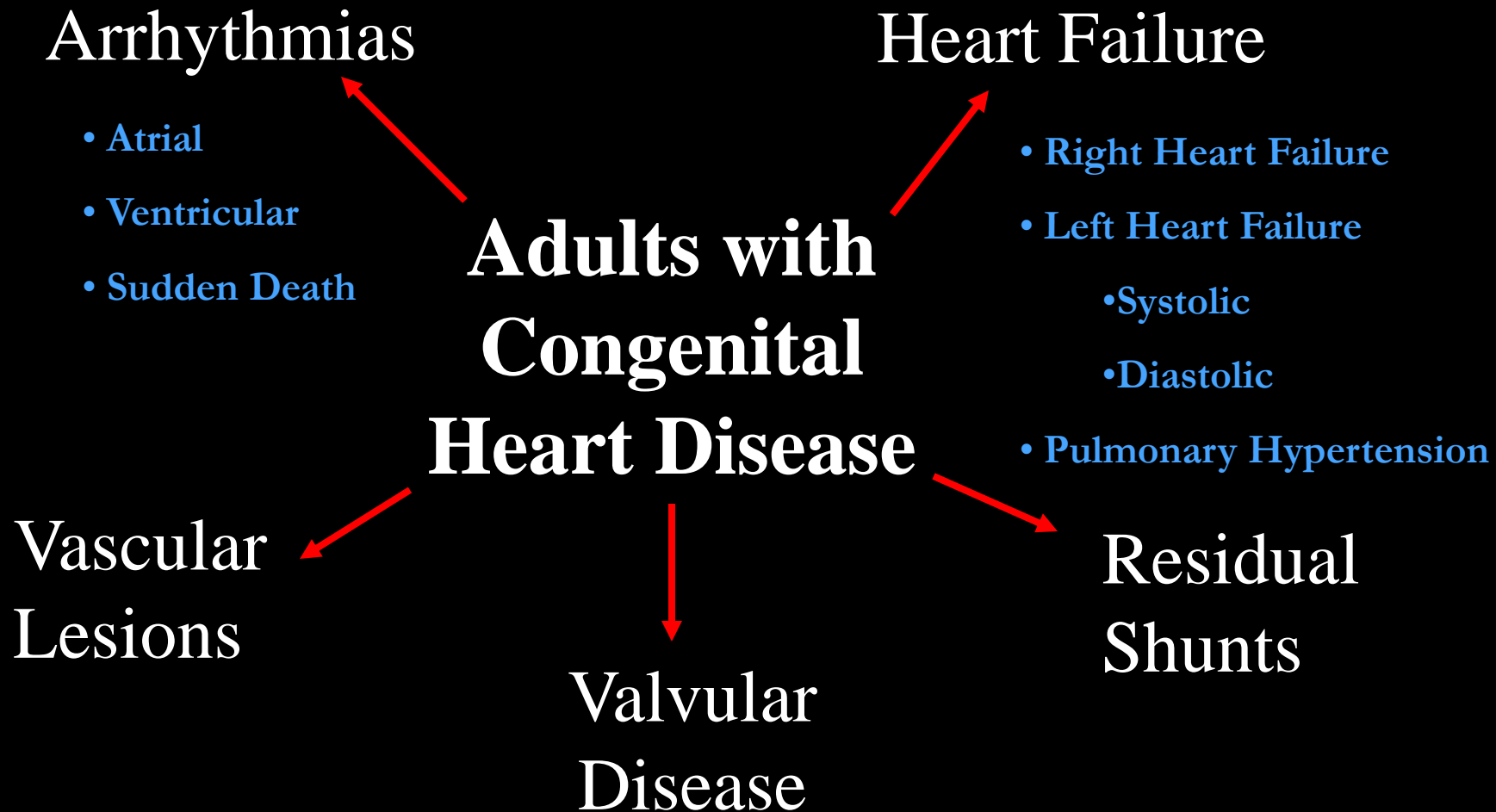
**ACHD**

CHD PATIENTS

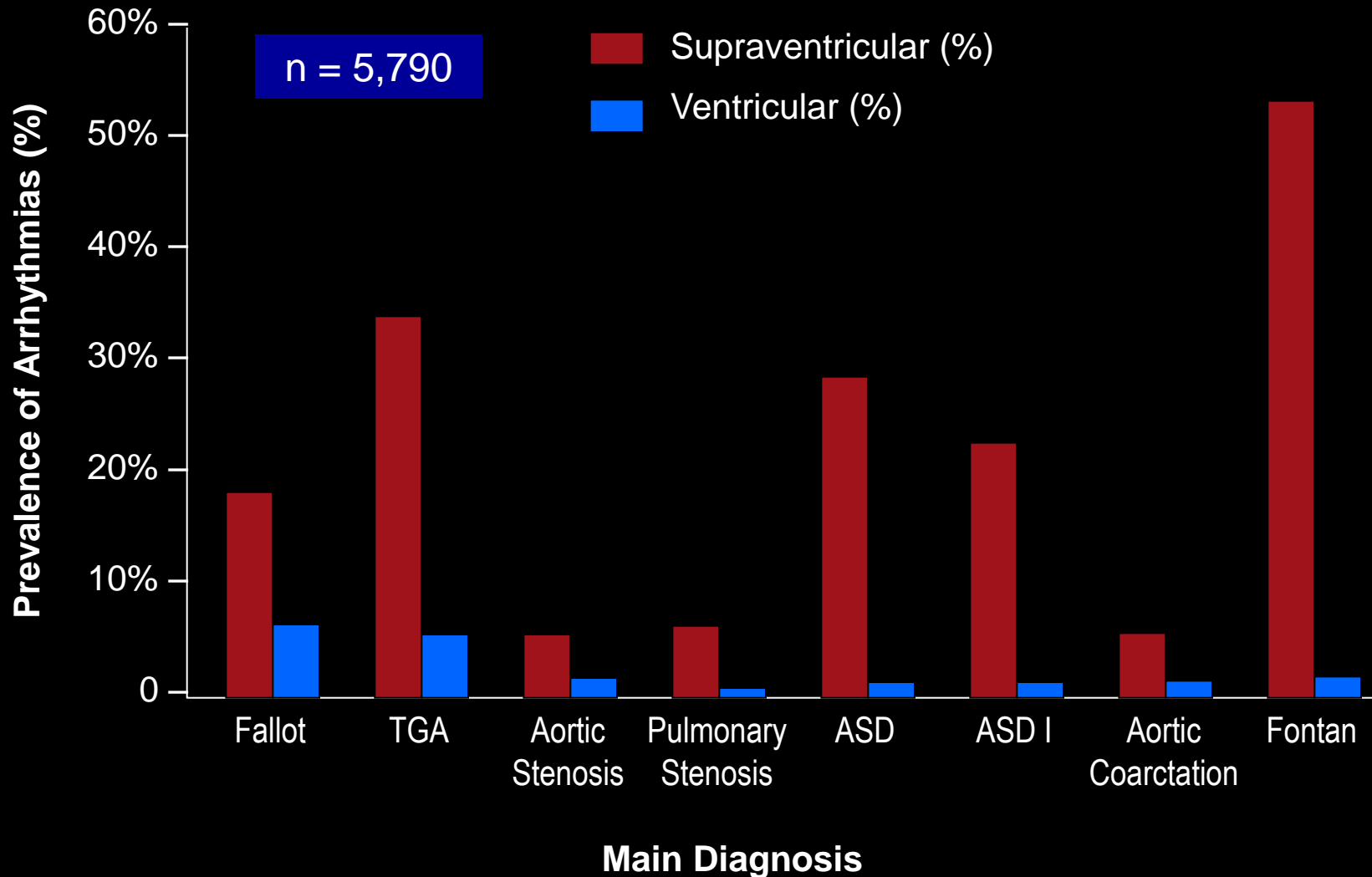
GT Surgery

# Long –Term Complications

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# Prevalence of Arrhythmias in ACHD Patients

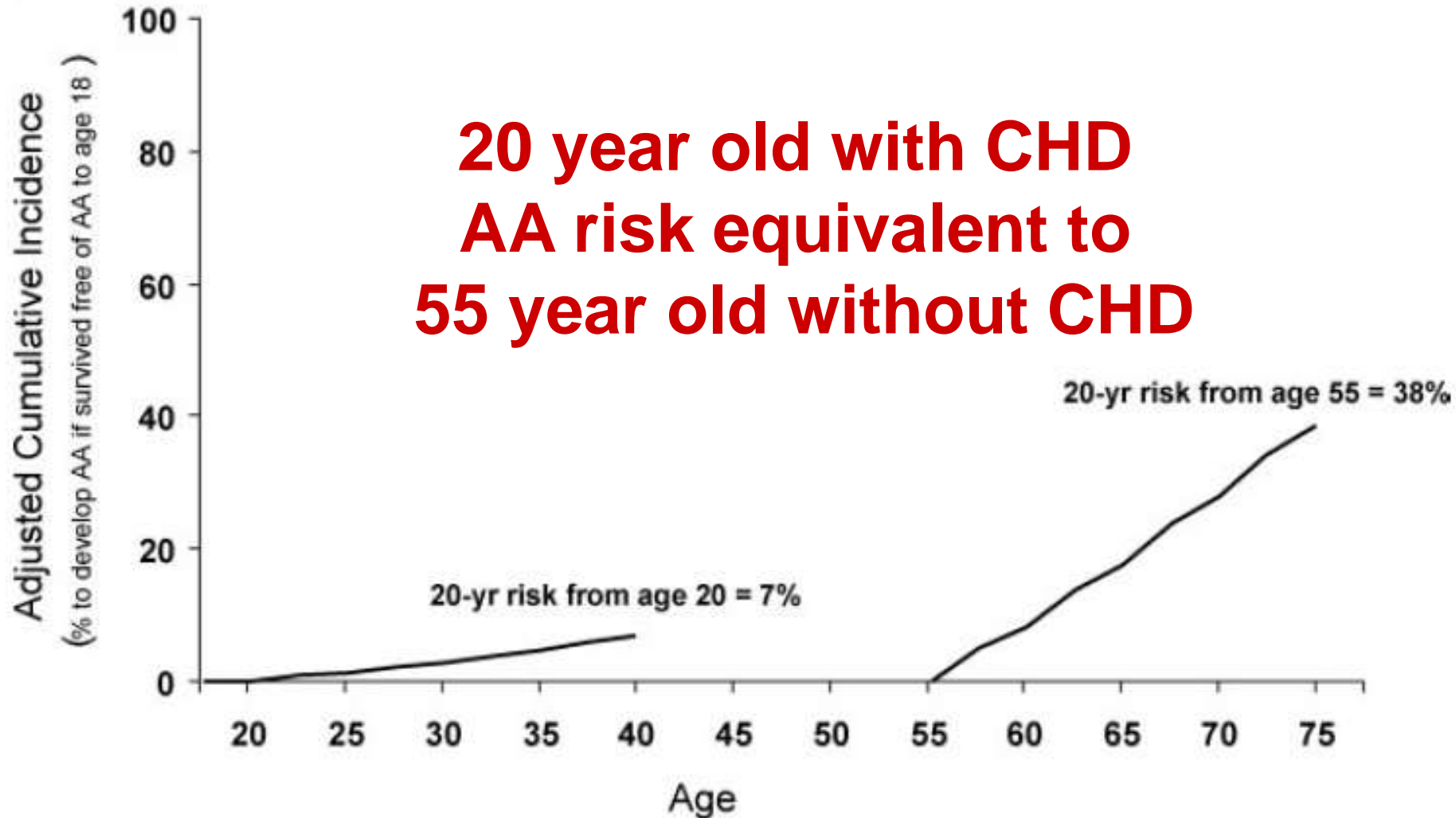


# Cumulative Risk of Atrial Arrhythmia in ACHD

Period Risk In 5-Year Intervals, %

Age, y	5	10	15	20	25	30	35	40	45	50	Lifetime Risk* (95% CI)
<b>Severe CHD</b>											
20	3.7	8.4	12.8	18.0	22.7	30.5	37.0	43.3	50.4	57.1	63.0 (58.8–67.2)
25	4.9	9.5	15.1	20.1	28.3	35.1	41.8	49.2	56.3		62.6 (58.1–67.0)
30	5.0	10.9	16.3	25.1	32.3	39.5	47.5	55.1			61.8 (57.1–66.5)
35	6.3	12.0	21.3	29.1	36.7	45.2	53.2				60.3 (55.3–65.2)
40	6.2	16.4	24.9	33.2	42.5	51.3					59.0 (53.8–64.3)
45	11.1	20.3	29.4	39.5	49.1						57.5 (51.8–63.3)
50	11.0	21.8	33.8	45.2							55.2 (48.6–61.9)
55	12.5	26.5	39.7								51.3 (44.3–58.5)
60	16.6	32.4									46.3 (38.3–54.3)
65	19.6										36.9 (28.3–45.5)
70											22.7 (14.2–31.2)
<b>Other CHD</b>											
20	1.0	2.0	3.4	5.4	8.6	12.9	17.8	23.9	31.0	38.8	46.7 (45.8–67.6)
25	1.0	2.5	4.5	7.8	12.2	17.1	23.4	30.5	38.4		46.5 (45.6–47.4)
30	1.5	3.6	6.9	11.4	16.4	22.7	30.0	38.1			46.2 (45.3–47.2)
35	2.1	5.5	10.1	15.2	21.7	29.1	37.4				45.7 (44.8–46.6)
40	2.7	8.2	13.4	20.1	27.8	36.2					44.8 (43.9–45.8)
45	4.9	10.4	17.4	25.5	34.3						43.3 (42.4–44.3)
50	5.9	13.4	21.9	31.4							41.0 (40.1–42.0)
55	8.1	17.4	27.7								38.2 (27.2–39.2)
60	10.4	21.9									33.6 (32.6–34.6)

# Atrial Arrhythmia Risk



# Adverse Events and Survival with CHD and Atrial Arrhythmias

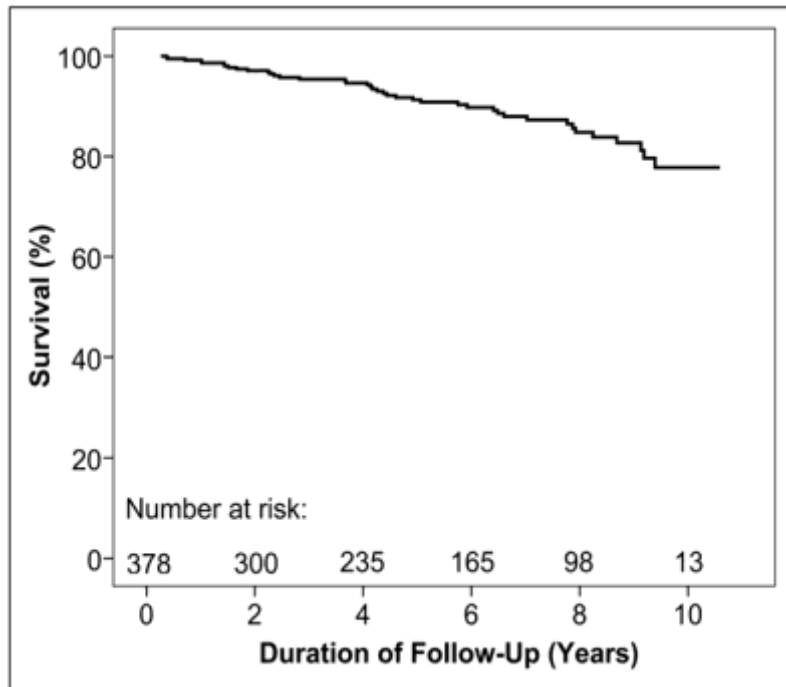


Figure 1. Kaplan–Meier survival curve for all-cause mortality in adults with congenital heart disease and atrial arrhythmias after the index visit.

Yap et al. AJC 2011; 108:723-728

**ANY ADVERSE EVENT**  
2.50 (2.38, 2.62)

**MORTALITY**  
1.47 (1.37, 1.58)

**MORBIDITY**  
2.21 (2.07, 2.36)

**Stroke**  
1.55 (1.42, 1.68)

**Heart failure**  
2.64 (2.44, 2.85)

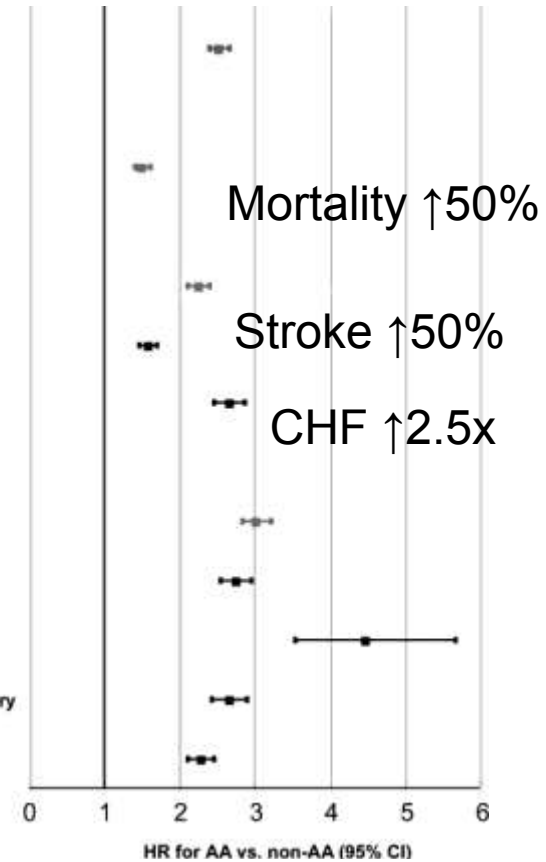
**INTERVENTIONS**  
3.00 (2.81, 3.20)

**Congenital cardiac surgery**  
2.72 (2.52, 2.93)

**Arrhythmia surgery**  
4.46 (3.51, 5.64)

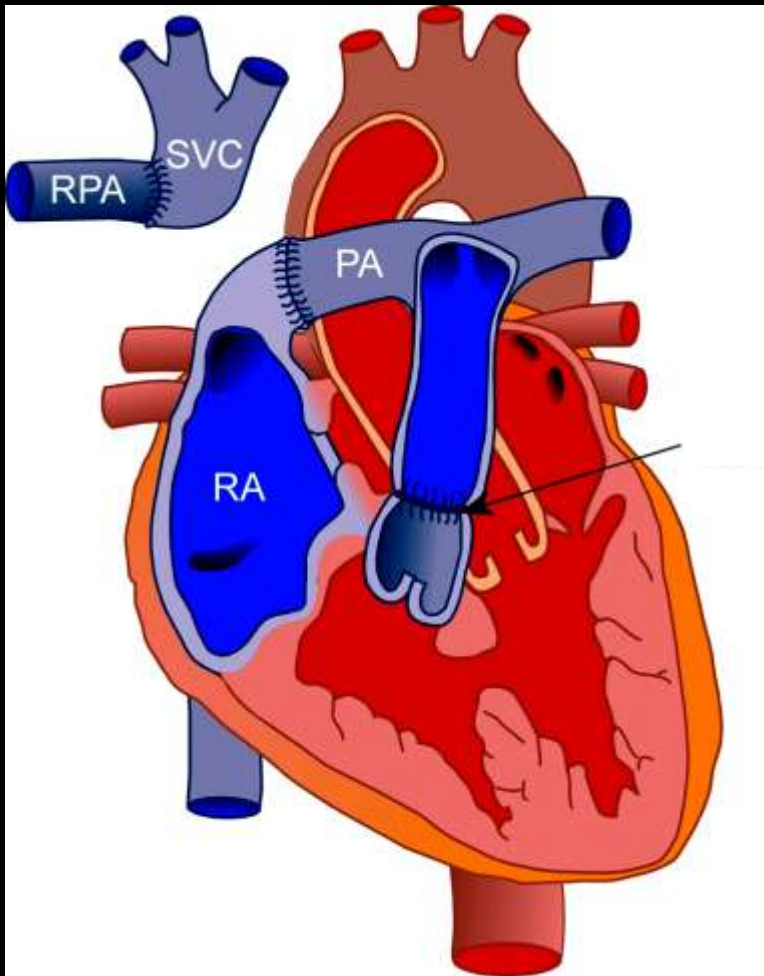
**Non-congenital cardiac surgery**  
2.62 (2.40, 2.88)

**Cardiac catheterization**  
2.25 (2.07, 2.44)

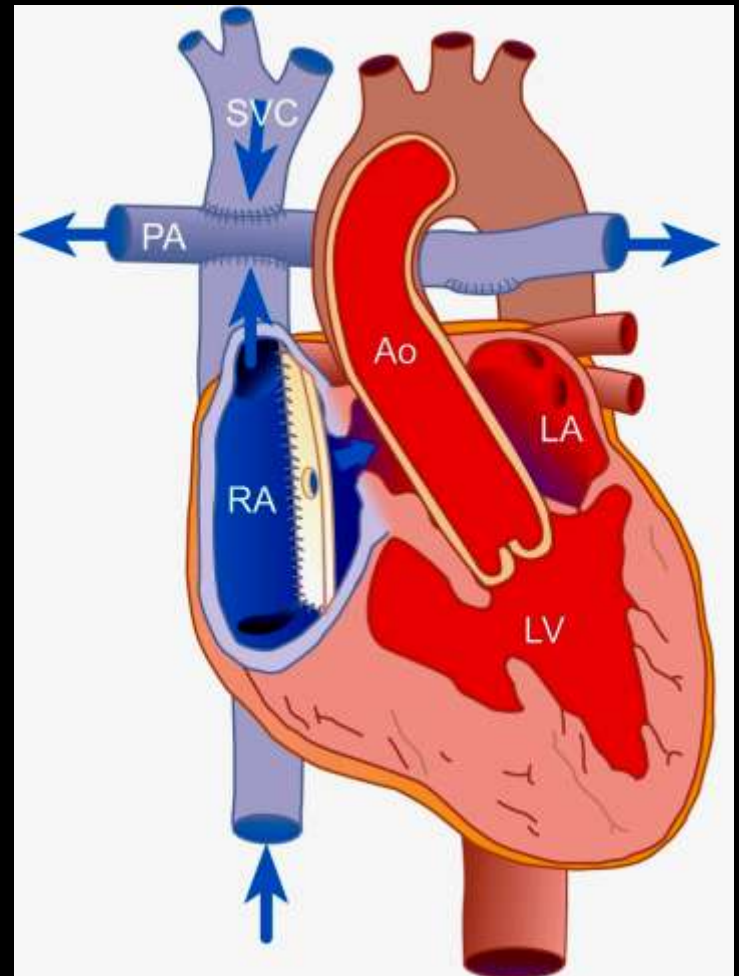


Bouchardy et al. Circulation 2009; 120:1679-1686

# Single Ventricle/Fontan

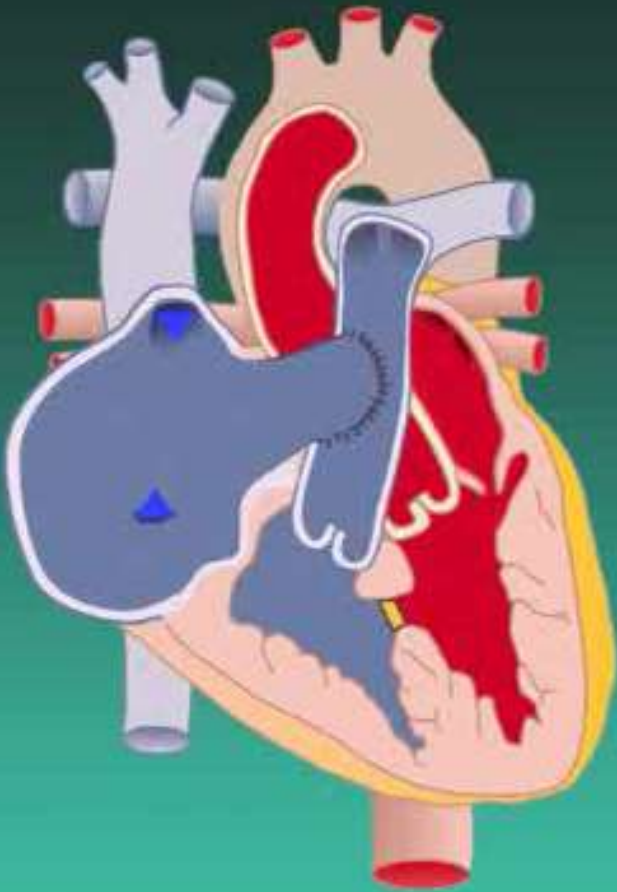


Modified Fontan



Lateral Tunnel

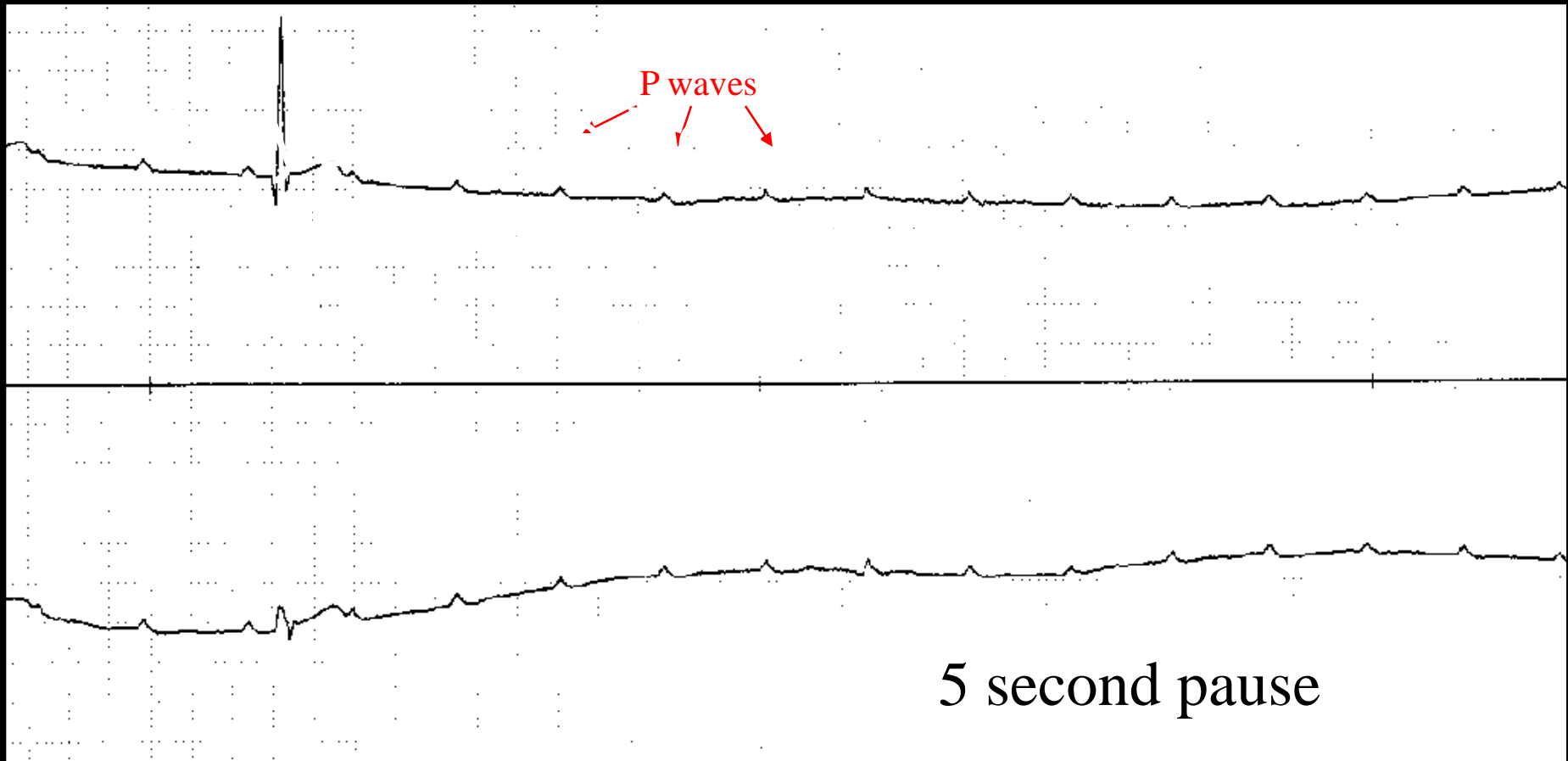
# Single Ventricle/Fontan



# Single Ventricle/Fontan

---

Holter monitor



Mary Rutan Hospital  
Bellefontaine, Ohio  
PATIENT PROGRESS NOTES



EMR  
190957

025Y M  
3 A.  
1.

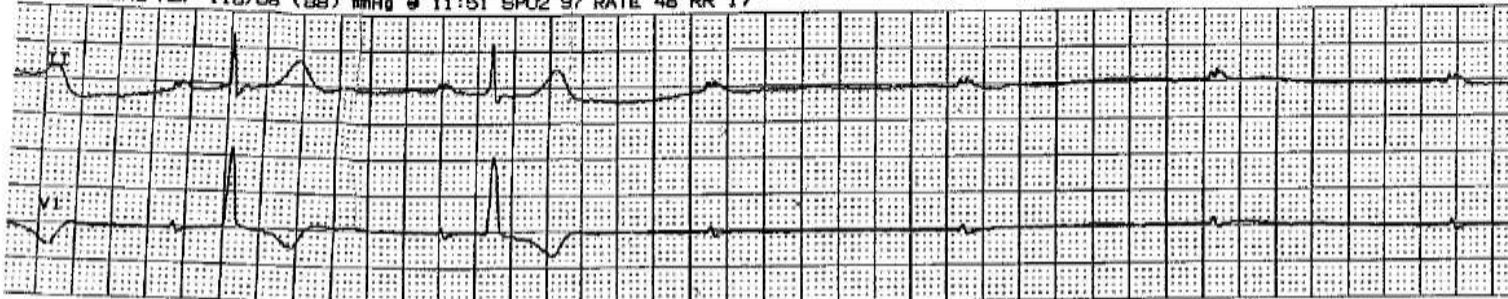
02/23/09

Date

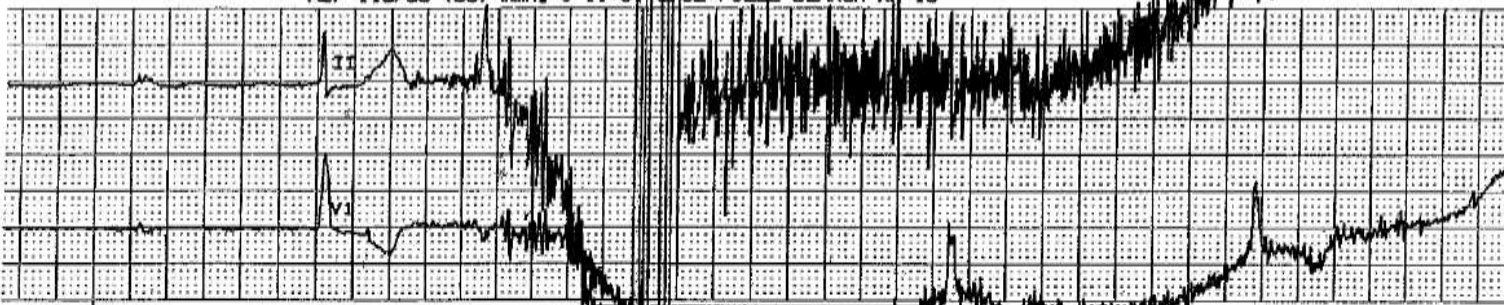
2/23/09

Notes Should Be Signed by Physician

ALARM SAVED #ASYSTOLE# E 00180957 23-FEB-2009 11:58:16  
ALM VOL 70X 025 MM/S HR 0 ASYSTOLE MONITORING NEP 118/68 (88) mmHg @ 11:51 SPO2 97 RATE 48 RR 17  
LL PVC 0 ST II -0.5 (J + 60ms)



ALARM #ASYSTOLE# ER-C 00180957 23-FEB-2009 11:58:26 ALM VOL 70X  
025 MM/S HR 0 ASYSTOLE MONITORING NEP 118/68 (88) mmHg @ 11:51 SPO2 PULSE SEARCH RR 15  
LL PVC 0 ST II -0.5 (J + 60ms)



ALARM #ASYSTOLE# ER 00180957 23-FEB-2009 11:58:3  
025 MM/S HR 0 ASYS 0 ST II -0.5 (J + 60ms) MON  
NEP 118/68 (88) mmHg @ 11:51 SPO2 97 RATE 44 RR 25



10-DEC-1976 (35 yr)  
Male Caucasian  
Room: RE14  
Loc: 88

Vent. rate 127 BPM  
PR interval \* ms  
QRS duration 108 ms  
QT/QTc 336/488 ms  
P-R-T axes \* 191 11

ABNORMAL RHYTHM-TYPE UNDETERMINED  
PROBABLE SLOW SVT  
ACCELERATED JUNCTIONAL RHYTHM WITH RETROGRADE CONDUCTION CANNOT BE EXCLUDED  
ASSUMING THAT ELECTRODES ARE PROPERLY PLACED, SUSPECT MESOCARDIA WITH HYPERTROPHY OF THE SYSTEMIC VENTRICLE

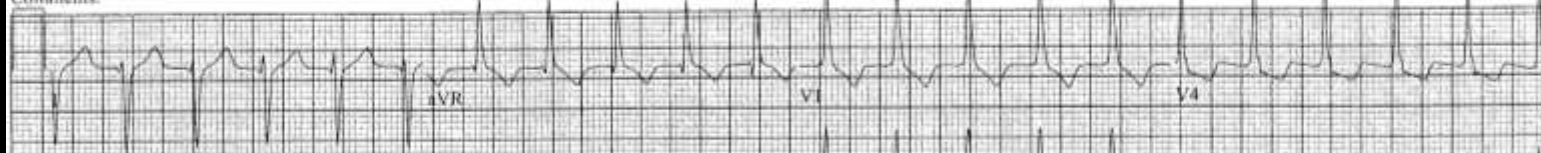
Reconfirmed by LEIER, MD (13), C.V. (7) on 10/15/2012 2:51:15 PM

Technician:  
Test ind:95

Referred by:

Confirmed By: C.V. LEIER, MD (13)

Comments:



Patient ID 907123024 Gender Male Date of Birth 12/10/1976 (36 years) Phone 734-604-2751 Monitor Braemar ER920W  
Physician CURTIS J DANIELS Practice OHIO STATE UNIVERSITY-ROSS  
Diagnosis Paroxysmal supraventricular tachycardia

Period (30 Days) 06/01/2013 - 06/30/2013  
Event Counts  
**Critical: 1** Total: 4  
**Serious: 0** Patient: 3  
**Stable: 3** Auto: 1

### Event Summary

**1** Rec: 06/01/2013 02:32 PM Sinus Rhythm w/ PVC(1)/Lead Loss Stable



Symptom: Baseline  
Activity: Wireless Event  
Trans: 06/01/2013 02:34 PM  
Type: Patient-Activated  
HR: 93.2 BPM

Comments: Tech: Toye Mason, CCT

**2** Rec: 06/15/2013 09:19 PM Sinus Rhythm w/ 10 Beats Of V-Tach/ PVCs (5) Critical



Symptom: Auto Detect- Racing Hear  
Activity: Sitting  
Trans: 06/15/2013 09:33 PM  
Type: Auto-Detected  
HR: 175.7 BPM  
Dr. Notified - See Event Report

Comments: Tech: Tim Miller

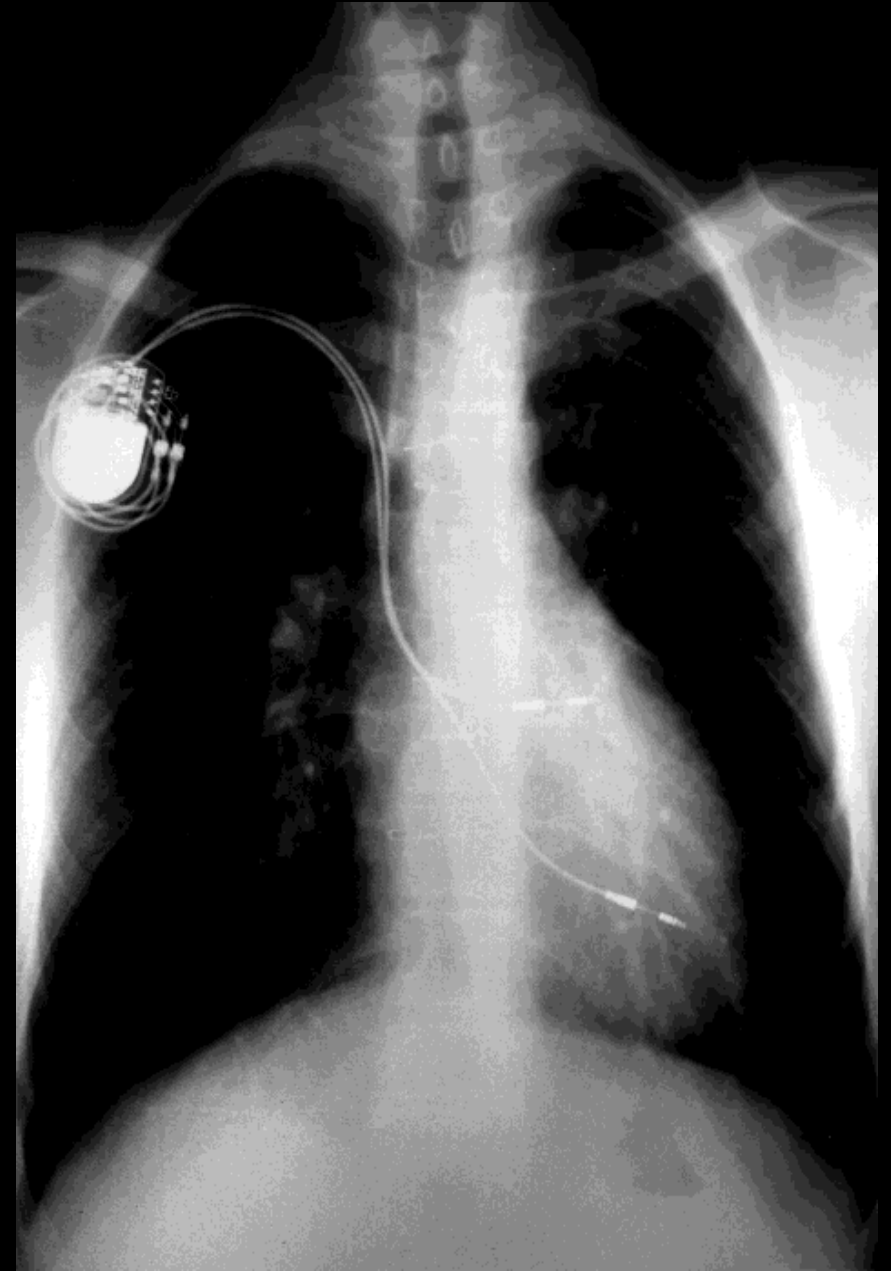
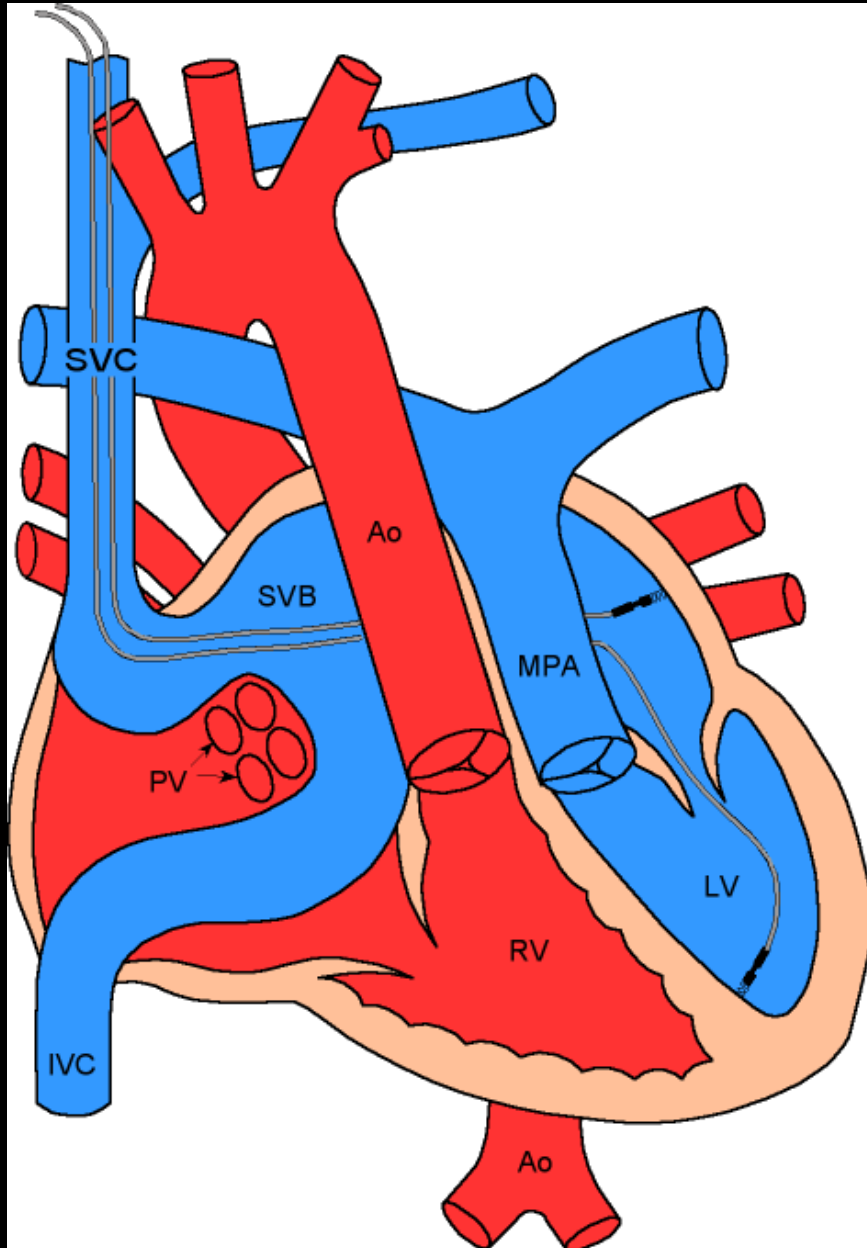
**3** Rec: 06/15/2013 10:00 PM Sinus Rhythm -Sinus Tachycardia w/PAC Stable

Symptom Follow Up: Critical - Tired, Headache  
Activity Standing  
Comments Tech: Jose John

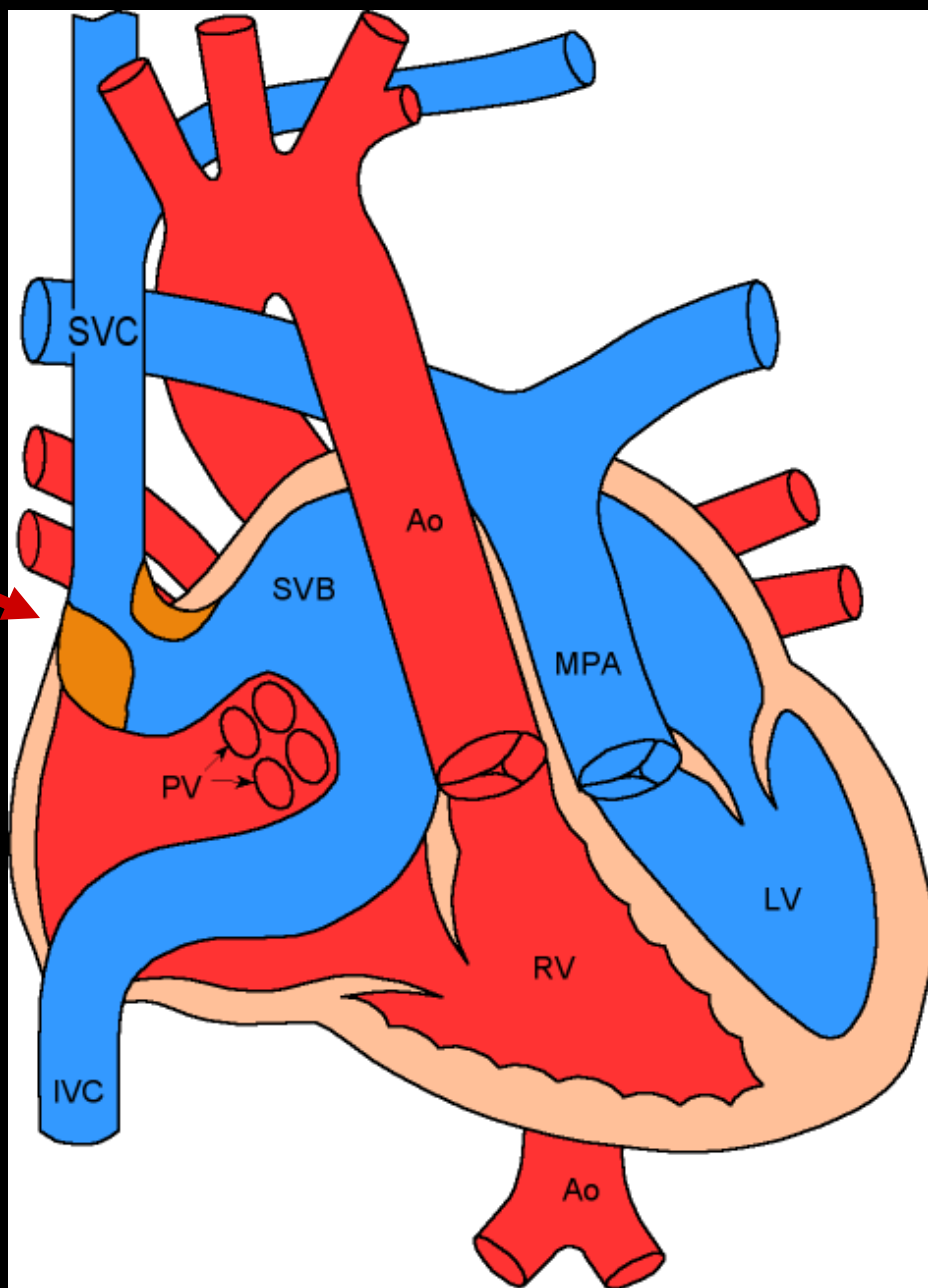
Type Patient-Activated  
Transmitted 06/15/2013 10:07 PM  
HR 98.8-102.2 BPM

**4** Rec: 06/24/2013 12:54 PM Junctional Tachycardia Stable

# D-TGA/Atrial Switch



# SVC Baffle Obstruction



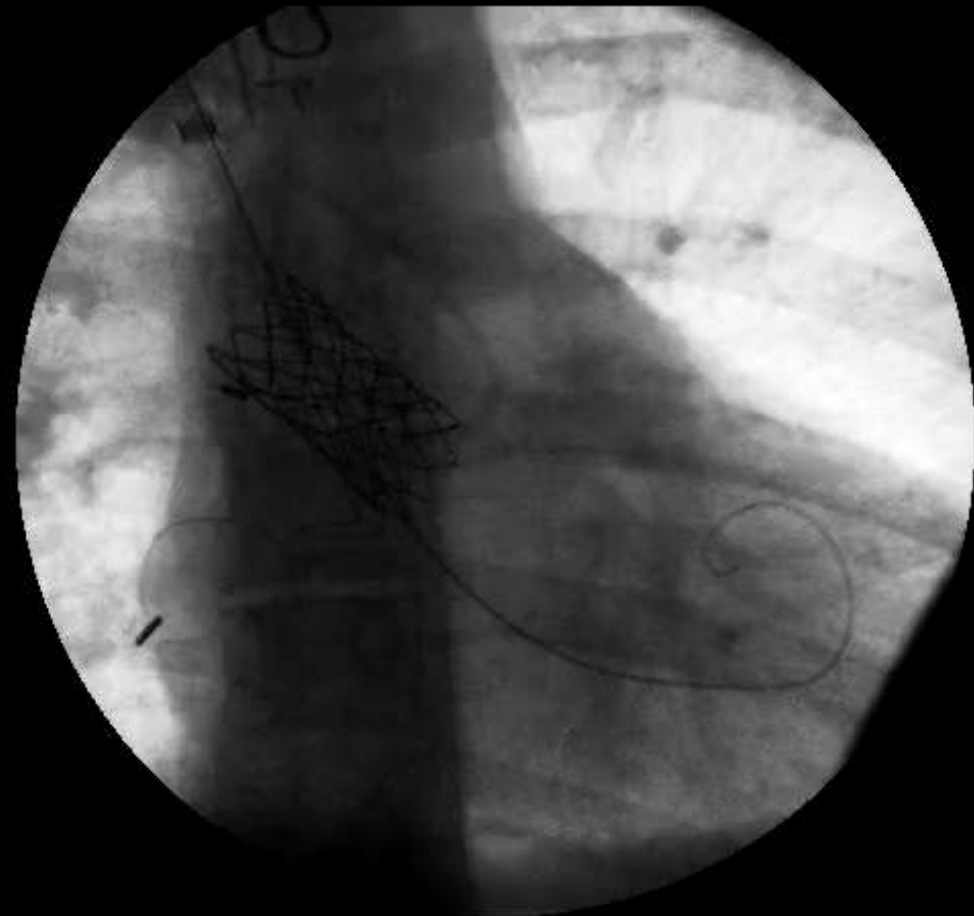
24 yo D-TGA/Mustard  
referred after unable to  
place pacemaker wire

# 24 yo D-TGA – Mustard

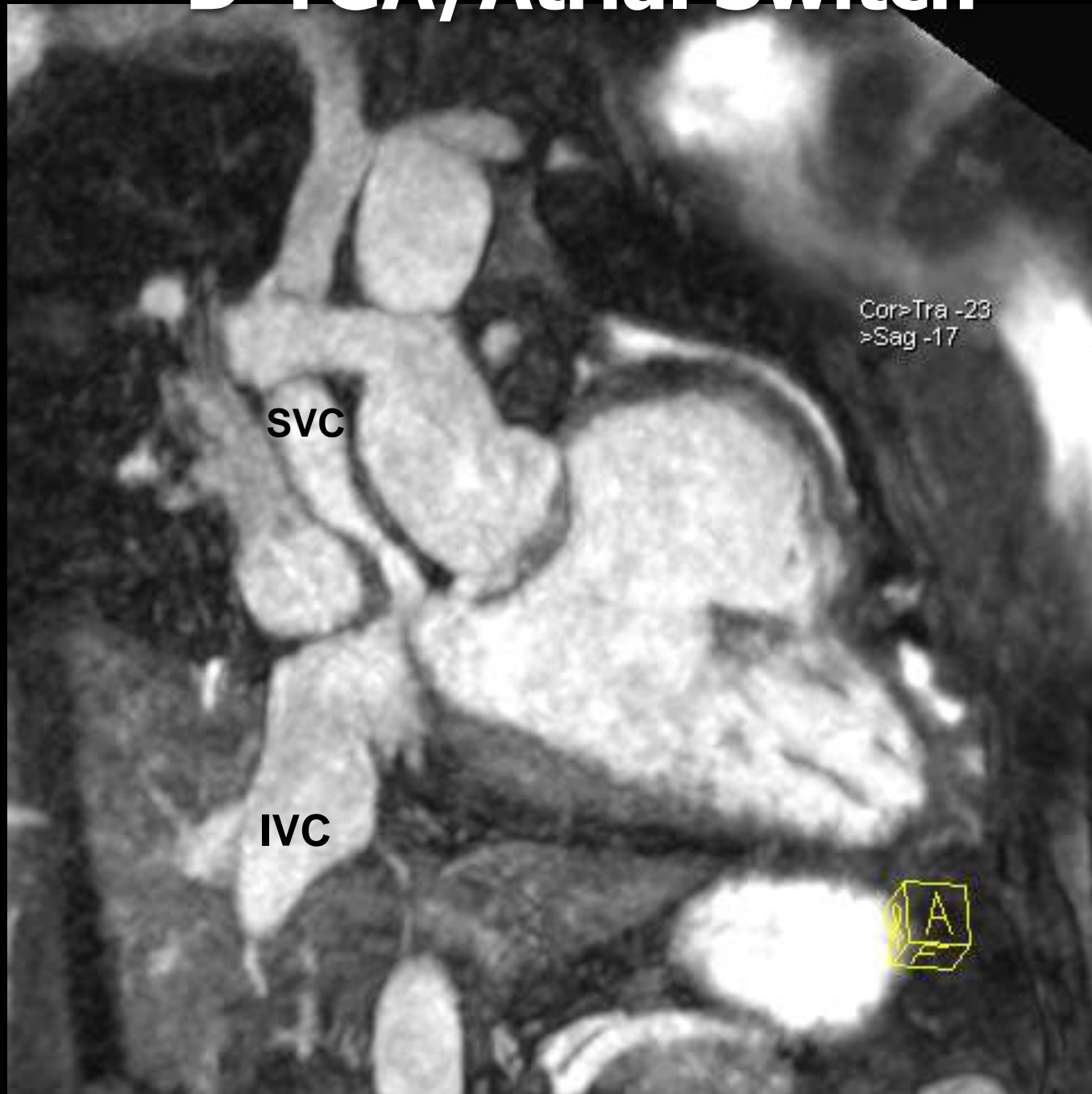
Lossy compression - not intended for diagnosis



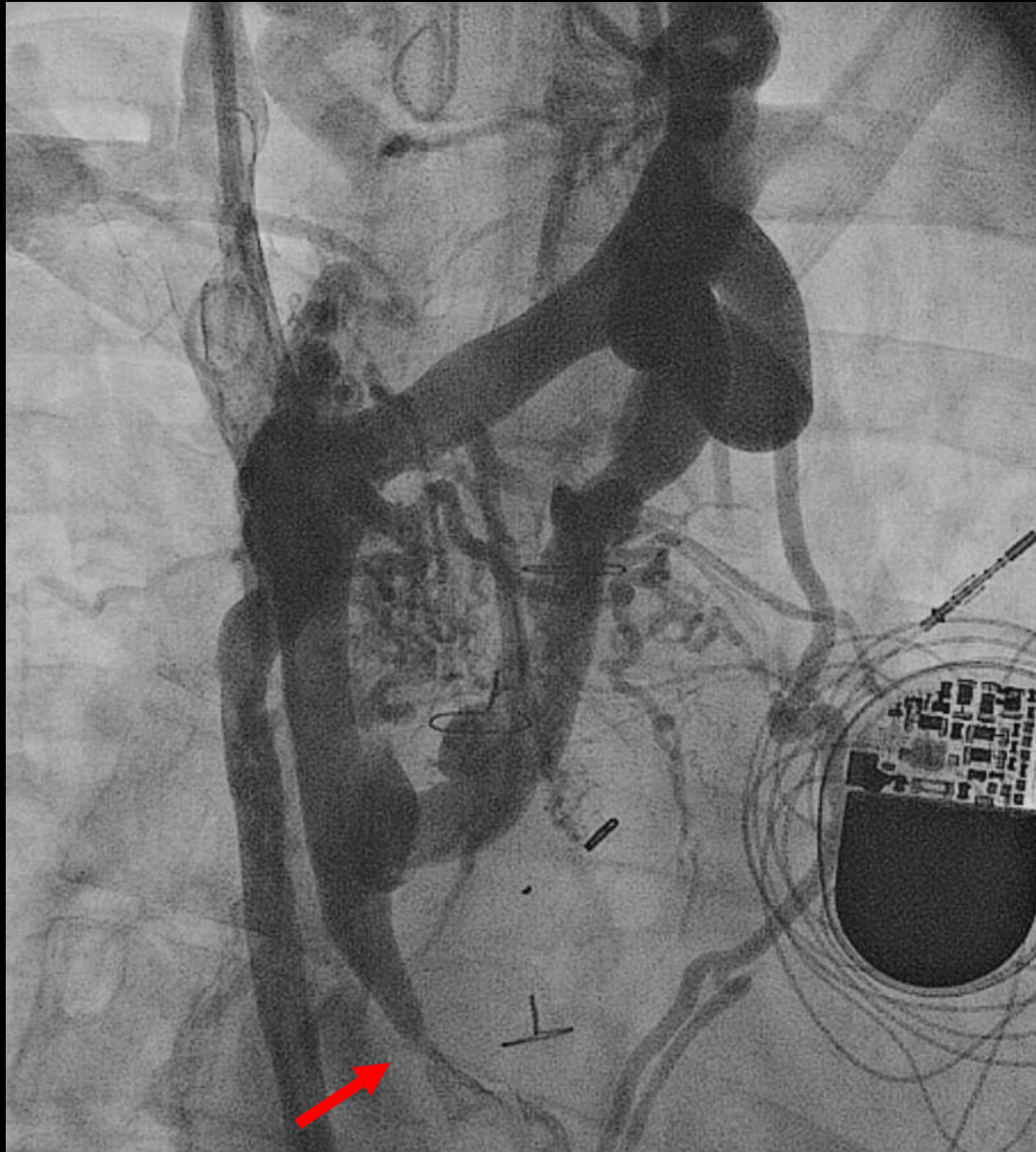
Lossy compression - not intended for diagnosis



# D-TGA/Atrial Switch



# 24 yo D-TGA/Atrial Switch with SVC Obstruction



CSN:



25mm/s 10mm/mV 150Hz 7.1.1 12SL 237 CID: 1

EID:136 EDT: 10:02 03-NOV-2011 ORDER:

ACCOUNT: 607793816

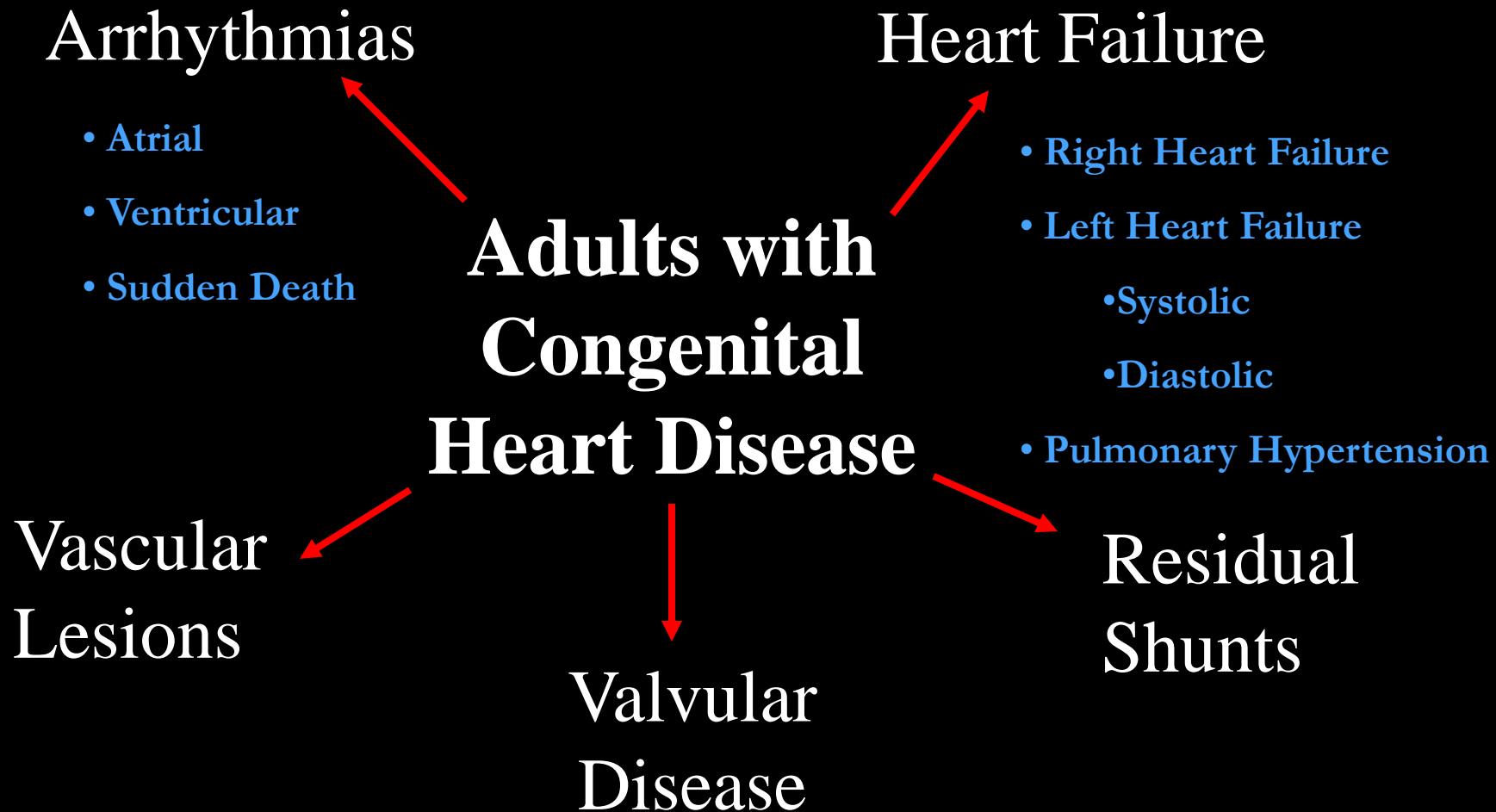
# Rate of Inducible Ventricular Arrhythmia in Adults With Congenital Heart Disease

Shane F. Tsai, MD<sup>a,b,c,\*</sup>, David P. Chan, MD<sup>a,b</sup>, Pamela S. Ro, MD<sup>a,b</sup>, Bethany Boettner, MA<sup>a</sup>, and Curt J. Daniels, MD<sup>a,b,c</sup>

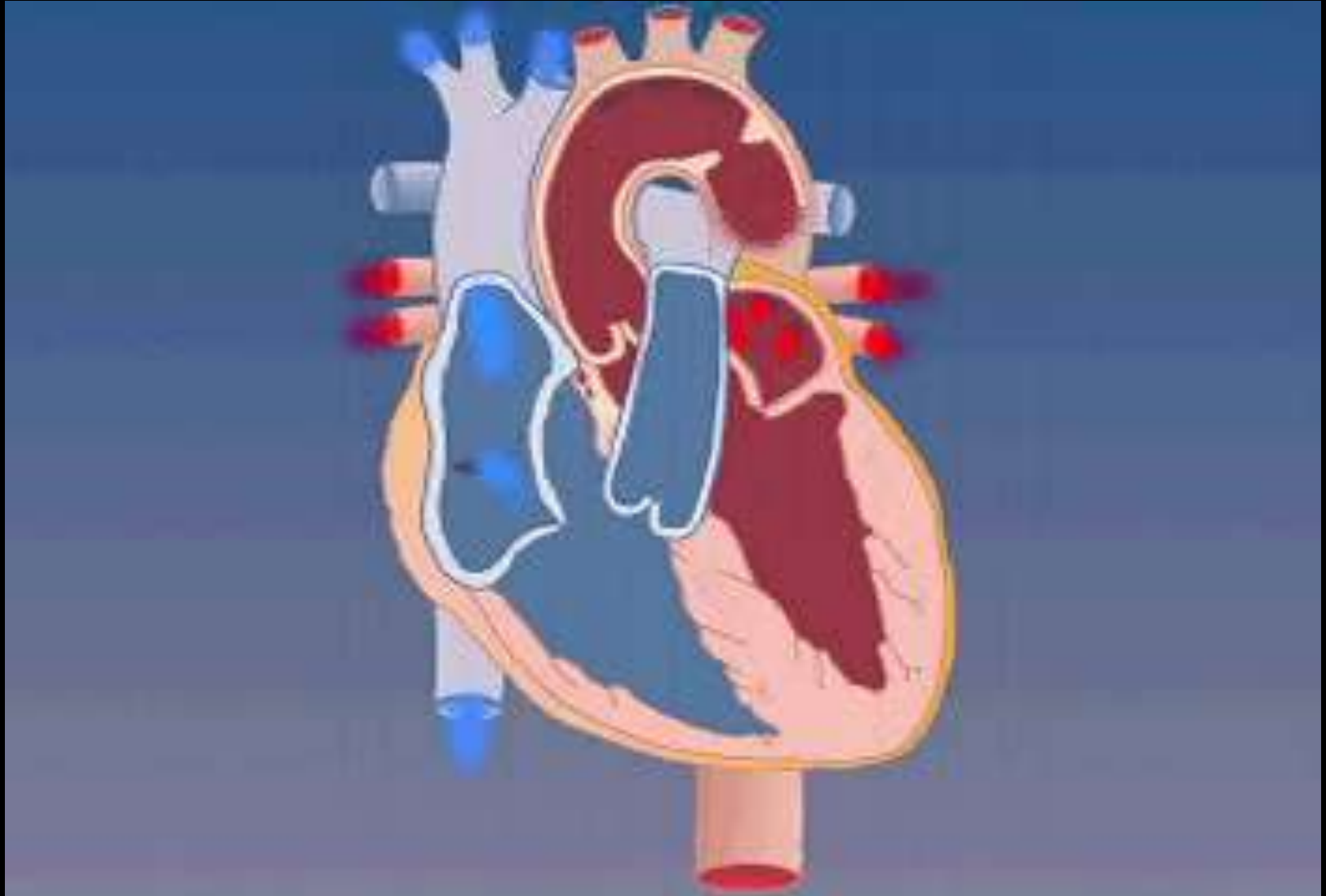
Patients with adult congenital heart disease are at increased risk of ventricular arrhythmia (VA) and sudden cardiac death, although no clear predictors have been found. Ventricular programmed stimulation has been shown to predict clinical ventricular tachycardia and sudden death events, but the role of screening electrophysiology studies (S-EPSs) in this population remains poorly defined. Therefore, we sought to determine the prevalence of inducible VA and to evaluate the clinical predictors in a heterogeneous group of patients with adult congenital heart disease ( $\geq 18$  years old) undergoing S-EPSs at preoperative or interventional cardiac catheterization. Studies for the primary evaluation of clinical VA were excluded. The demographic, clinical, and diagnostic findings were compared between the patients with positive and negative findings. From 2005 to 2009, 80 patients (mean age  $30 \pm 9$  years) underwent S-EPSs, and 23 had inducible VA. The diagnoses for those with studies positive for VA included tetralogy of Fallot ( $n = 12$ ), d-transposition of the great arteries ( $n = 6$ ), pulmonary stenosis ( $n = 2$ ), double outlet right ventricle ( $n = 1$ ), double inlet left ventricle ( $n = 1$ ), and Ebstein's anomaly ( $n = 1$ ). Men were significantly more likely to have a S-EPS positive for VA ( $p = 0.015$ ). Increasing QRS duration, decreasing peak oxygen uptake (percentage of predicted), and ventricular fibrosis with cardiovascular magnetic resonance imaging were significantly associated with studies positive for VA ( $p < 0.05$ ). Combined fibrosis and a peak oxygen uptake  $< 80\%$  of predicted had 100% sensitivity for positive VA findings. In conclusion, almost 30% of those with adult congenital heart disease undergoing S-EPSs had inducible VA. A prolonged QRS duration, diminished exercise capacity, and the presence of ventricular fibrosis were significantly associated with findings positive for VA and might improve patient selection for screening evaluations. © 2010 Elsevier Inc. All rights reserved. (Am J Cardiol 2010;106:730–736)

# Long –Term Complications

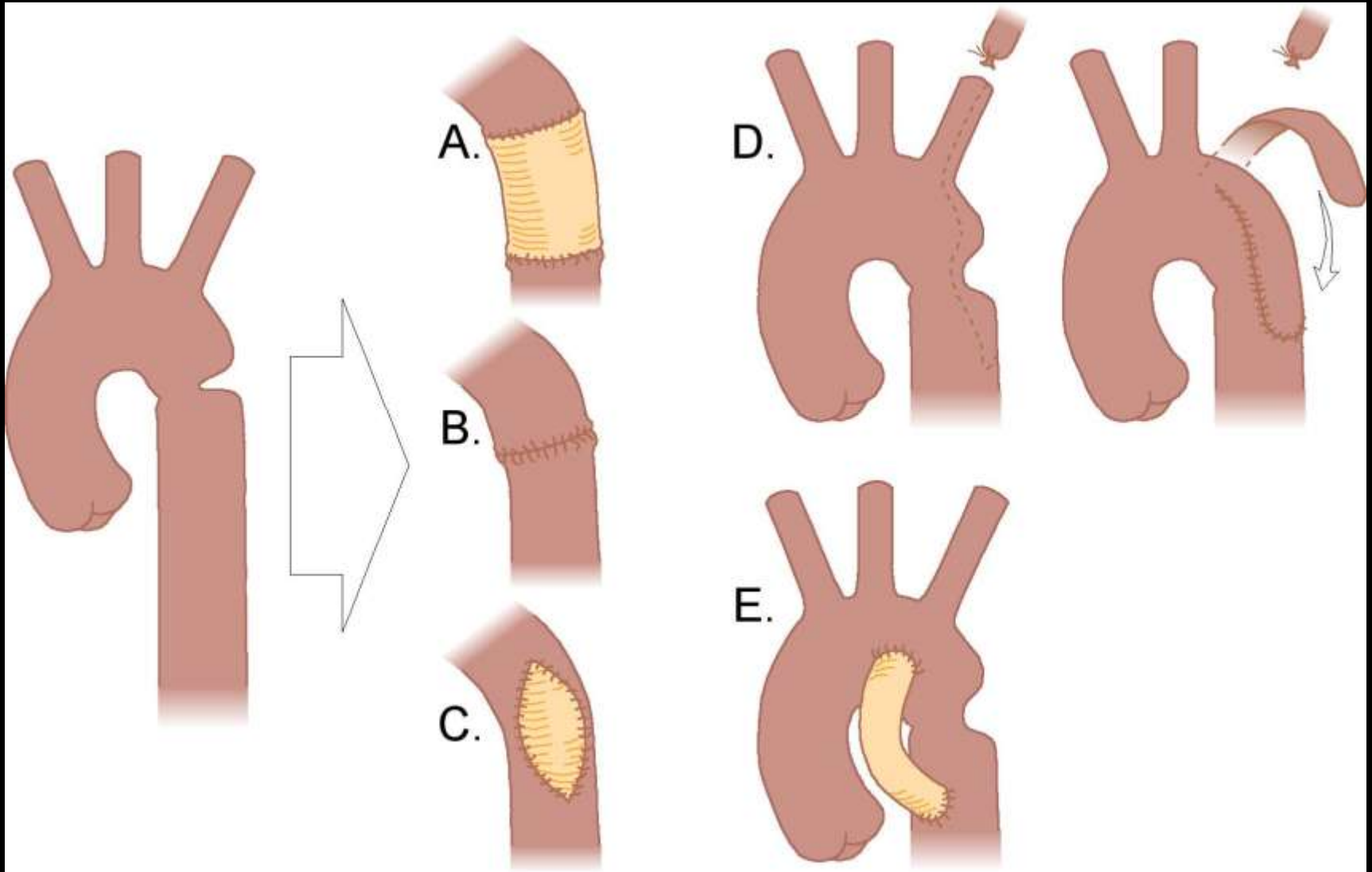
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# COA



# Coarctation of the Aorta - Surgery



**PRACTICE GUIDELINE: FULL TEXT**

## **ACC/AHA 2008 Guidelines for the Management of Adults With Congenital Heart Disease**

A Report of the American College of Cardiology/American Heart Association Task Force on Practice Guidelines (Writing Committee to Develop Guidelines on the Management of Adults With Congenital Heart Disease)

*Developed in Collaboration With the American Society of Echocardiography, Heart Rhythm Society, International Society for Adult Congenital Heart Disease, Society for Cardiovascular Angiography and Interventions, and Society of Thoracic Surgeons*

### WRITING COMMITTEE MEMBERS

Carole A. Wames, MD, FRCP, FACC, FAHA, Co-Chair; Roberta G. Williams, MD, MACC, FAHA, Co-Chair; Thomas M. Bashore, MD, FACC; John S. Child, MD, FACC, FAHA; Heidi M. Connolly, MD, FACC; Joseph A. Dearani, MD, FACC\*; Pedro del Nido, MD; James W. Fasules, MD, FACC; Thomas P. Graham, Jr, MD, FACC†; Ziyad M. Hijazi, MBBS, MPH, FACC, FSCAI‡; Sharon A. Hunt, MD, FACC, FAHA; Mary Etta King, MD, FACC, FASE§; Michael J. Landzberg, MD, FACC; Pamela D. Miner, RN, MN, NP; Martha J. Radford, MD, FACC; Edward P. Walsh, MD, FACC||; Gary D. Webb, MD, FACC¶

### TASK FORCE MEMBERS

Sidney C. Smith, Jr, MD, FACC, FAHA, Chair; Alice K. Jacobs, MD, FACC, FAHA, Vice-Chair; Cynthia D. Adams, RSN, PhD, FAHA#; Jeffrey L. Anderson, MD, FACC, FAHA#; Elliott M. Antman, MD, FACC, FAHA\*\*; Christopher E. Buller, MD, FACC; Mark A. Creager, MD, FACC, FAHA; Steven M. Ettinger, MD, FACC; Jonathan L. Halperin, MD, FACC, FAHA#; Sharon A. Hunt, MD, FACC, FAHA#; Harlan M. Krumholz, MD, FACC, FAHA; Frederick G. Kushner, MD, FACC, FAHA; Bruce W. Lytle, MD, FACC, FAHA#; Rick A. Nishimura, MD, FACC, FAHA; Richard L. Page, MD, FACC, FAHA; Barbara Riegel, DNSc, RN, FAHA#; Lynn G. Tarkington, RN; Clyde W. Yancy, MD, FACC, FAHA

### 6.12.3. Recommendations for Clinical Evaluation and Follow-Up

#### **CLASS I**

3. Every patient with coarctation (repaired or not) should have at least 1 cardiovascular MRI or CT scan for complete evaluation of the thoracic aorta and intracranial vessels. (*Level of Evidence: B*)

### 6.14.3. Recommendations for Key Issues to Evaluate and Follow-Up

#### **CLASS I**

5. Evaluation of the coarctation repair site by MRI/CT should be performed at intervals of 5 years or less, depending on the specific anatomic findings before and after repair. (*Level of Evidence: C*)

T 3



11

# Usefulness of Screening Cardiovascular Magnetic Resonance Imaging to Detect Aortic Abnormalities After Repair of Coarctation of the Aorta

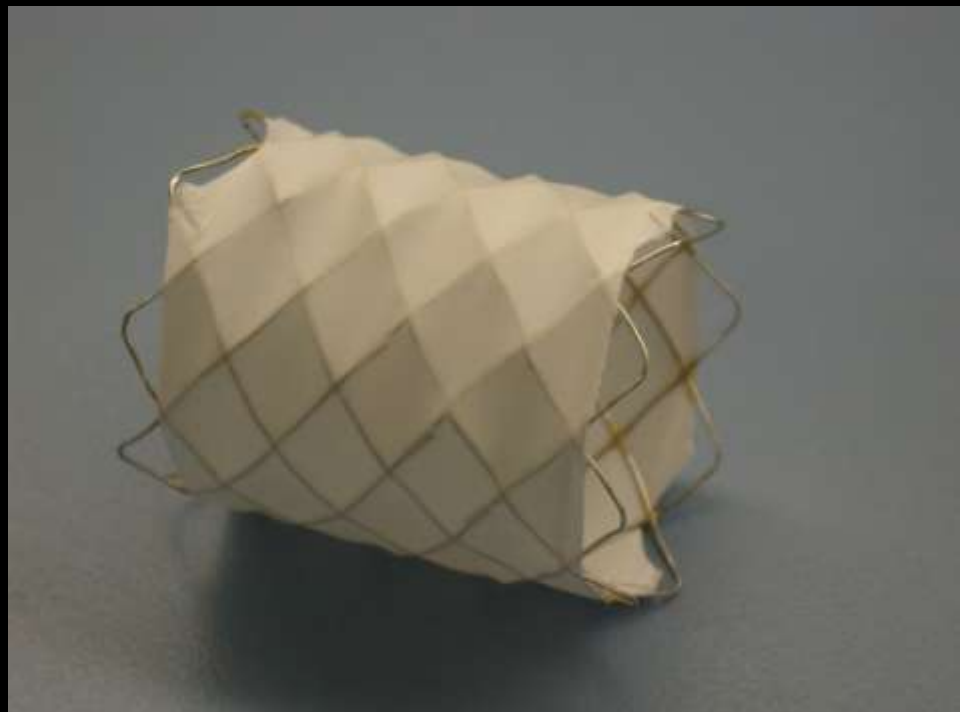
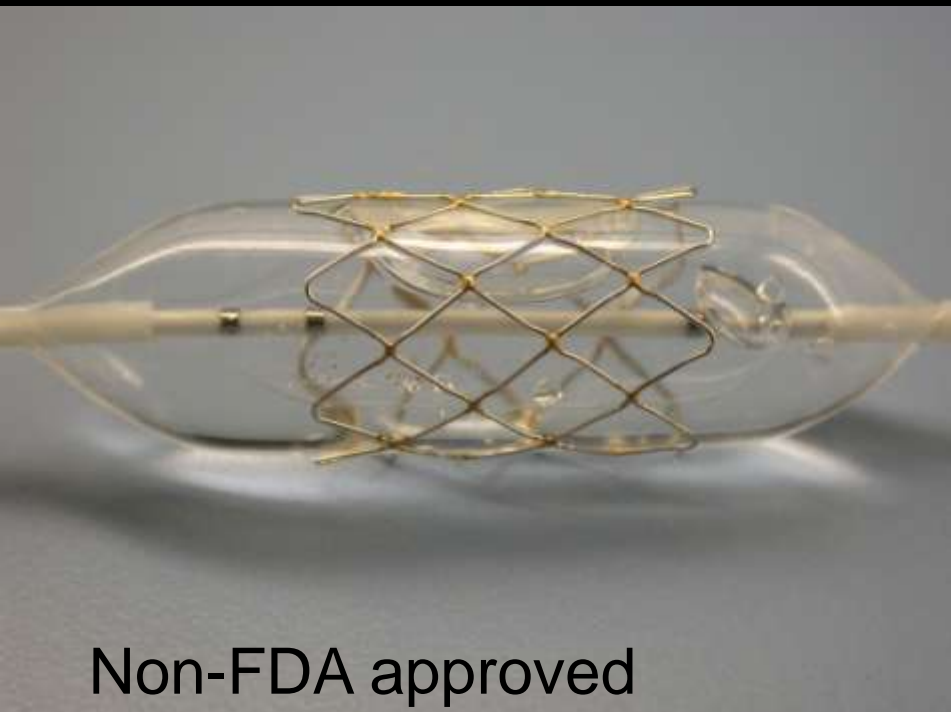
Shane F. Tsai, MD<sup>a,b,\*</sup>, Mira Trivedi<sup>b</sup>, Bethany Boettner, MA<sup>c</sup>, and Curt J. Daniels, MD<sup>a,b</sup>

Guidelines recommend screening cardiovascular magnetic resonance (Sc-CMR) imaging for all patients after coarctation of the aorta repair, although there are limited data verifying its clinical utility. Therefore, we sought to assess the value of Sc-CMR in detecting aortic complications and at-risk abnormalities after coarctation of the aorta repair and to identify significant risk factors. We reviewed 76 patients (mean age  $31 \pm 10$  years), including 40 with symptomatically indicated CMR (Sx-CMR) and 36 with Sc-CMR studies. CMR angiograms were evaluated for aortic abnormalities. Recoarctation was defined as residual narrowing/descending aorta at the diaphragm  $\leq 0.5$  (at risk  $\leq 0.75$ ), ascending aorta aneurysm as maximum ascending cross-sectional area/height  $\geq 10$  (at risk  $\geq 5$ ), and descending aorta aneurysm as maximum descending diameter/descending aorta at the diaphragm  $\geq 1.5$  (at risk  $\geq 1.25$ ). Aortic complications or abnormalities were found in 45 patients (59%). No patient met criteria for recoarctation (at risk 10 Sx-CMR vs 5 Sc-CMR). Significant risk factors included heart failure symptoms and female gender ( $p < 0.05$ ). One patient (Sc-CMR) had ascending aneurysm (at risk 17 Sx-CMR vs 8 Sc-CMR). Time from repair was a significant predictor ( $p < 0.05$ ). There were 10 patients (6 Sx-CMR vs 4 Sc-CMR) with descending aneurysm (at risk 8 Sx-CMR vs 7 Sc-CMR). Cardiovascular symptoms, hypertension, and echocardiogram were not predictive. In conclusion, >50% of patients undergoing Sc-CMR had aortic abnormalities, which was not significantly different from those undergoing Sx-CMR. In particular, Sc-CMR identified descending aorta aneurysms that were not predicted by clinical parameters or echocardiogram. © 2011 Elsevier Inc. All rights reserved. (Am J Cardiol 2011;107:297-301)

**28 yo s/p rCOA  
asymptomatic surveillance**

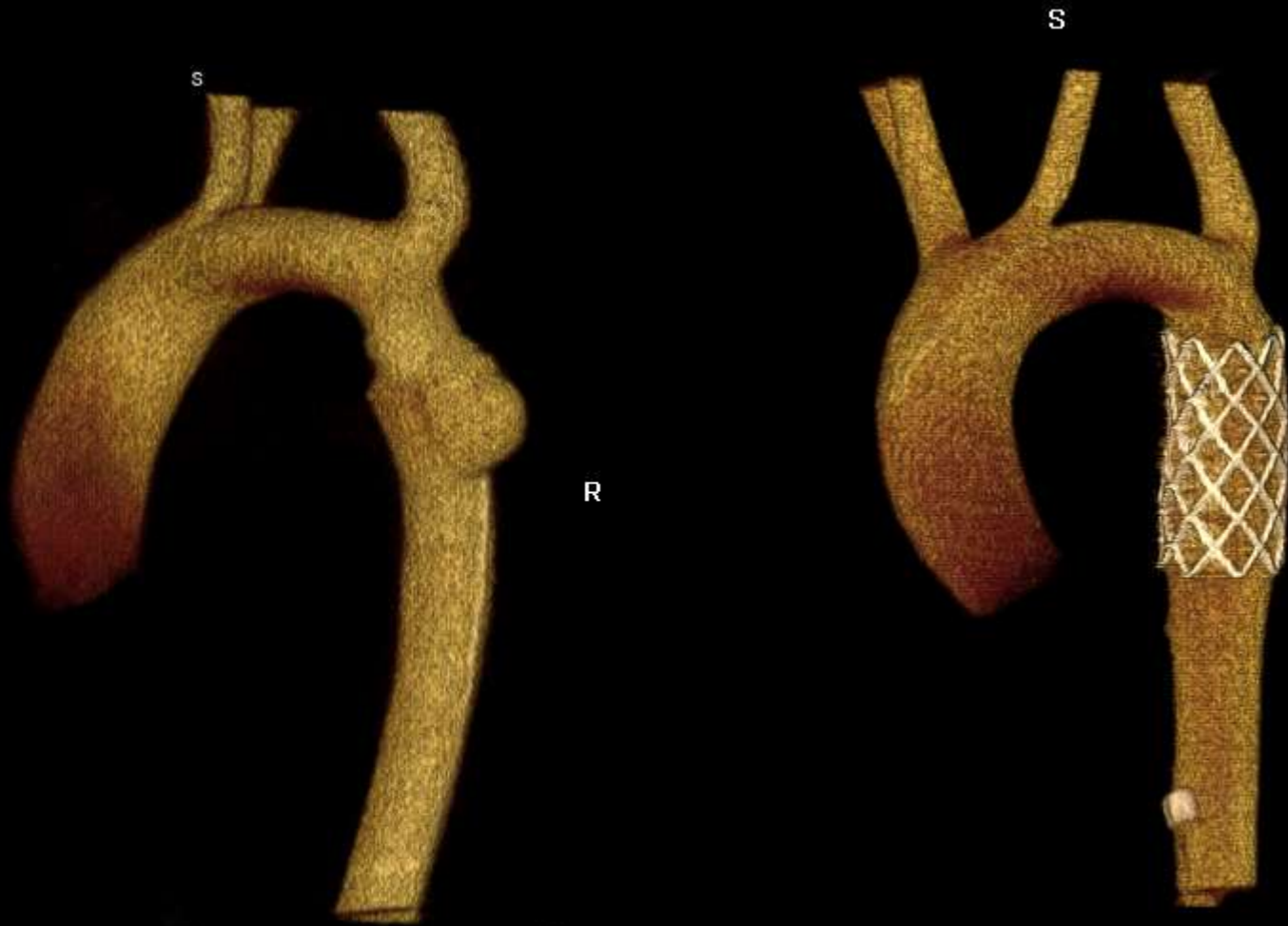


# e-PTFE Covered NuMED CP Stent & BIB Catheter



Non-FDA approved

# 28 yo s/p rCOA asymptomatic surveillance



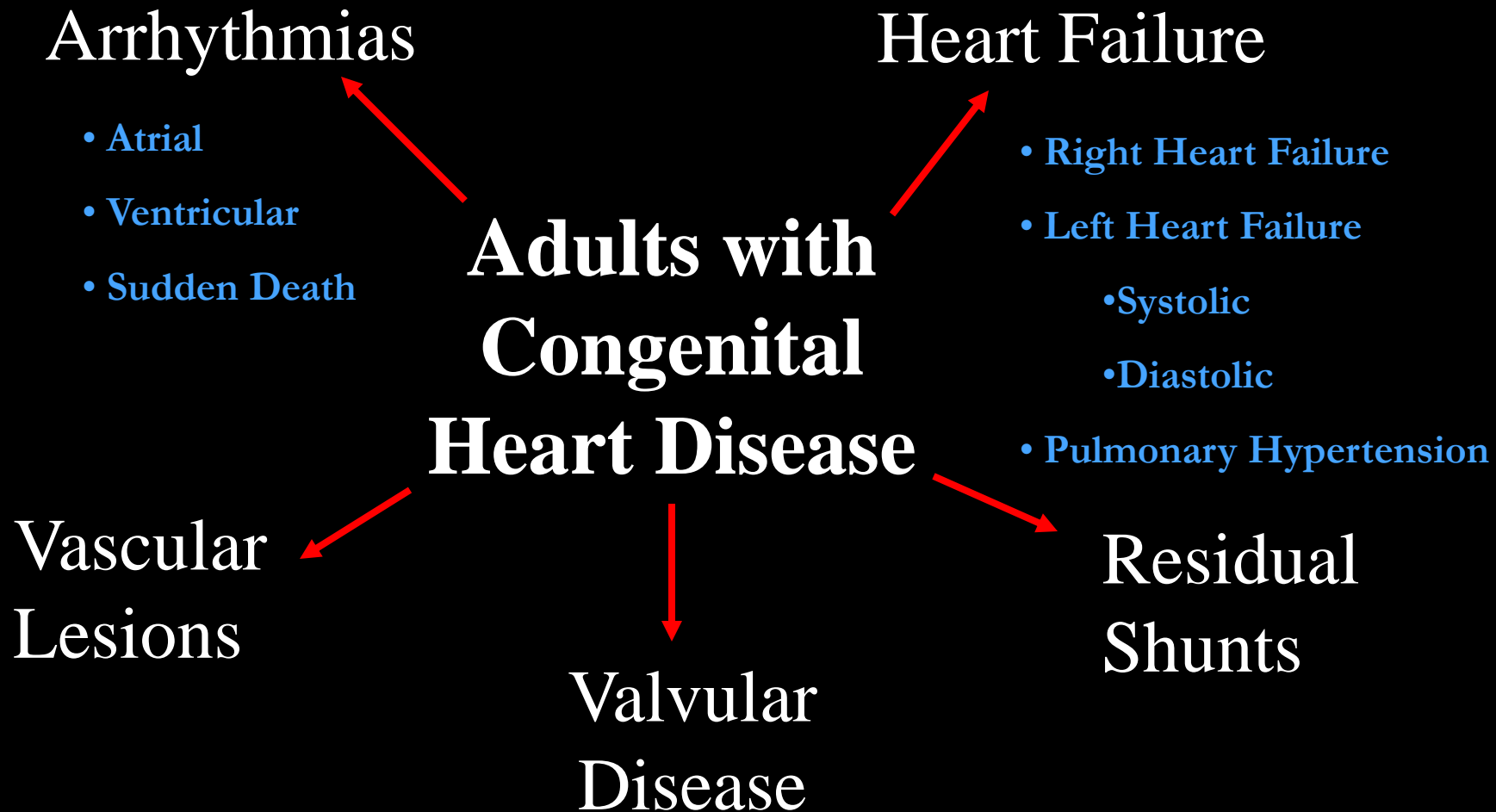
LAO90 CRA0

VR: LAO23 CRA0

Vitreac®  
W/L: 93/99  
Segmented  
VR: Vessel Only

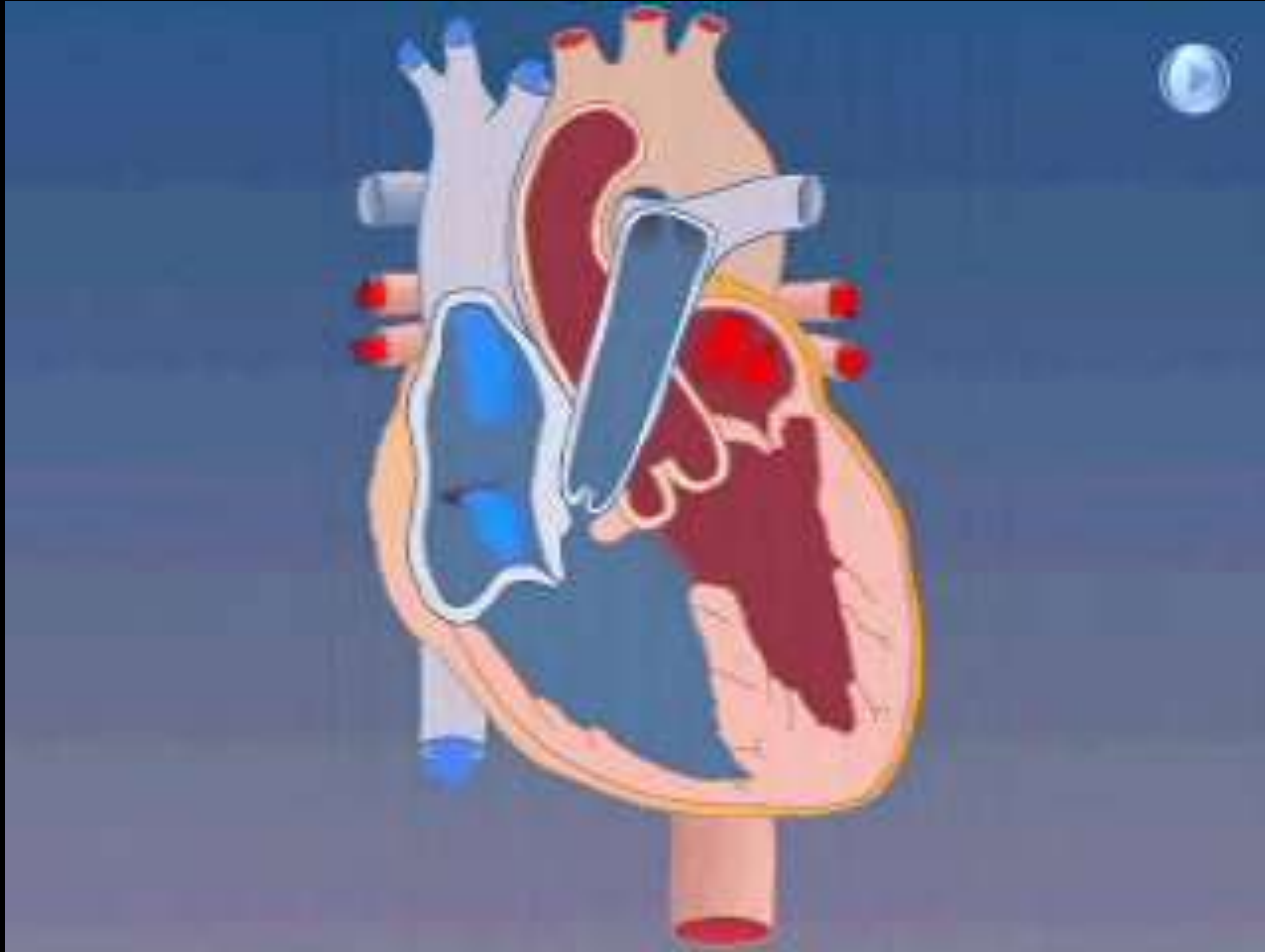
# Long –Term Complications

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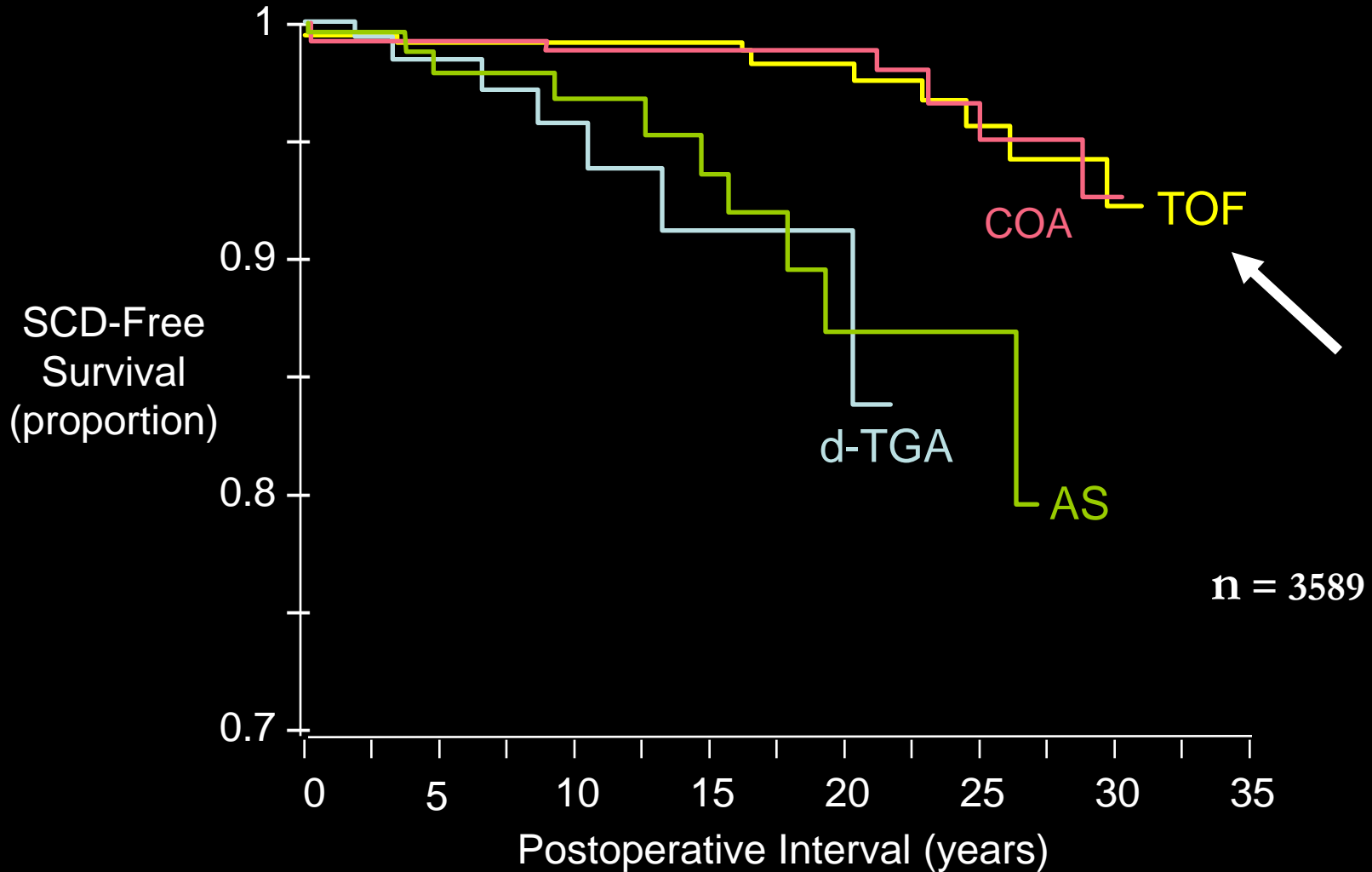


# rTOF

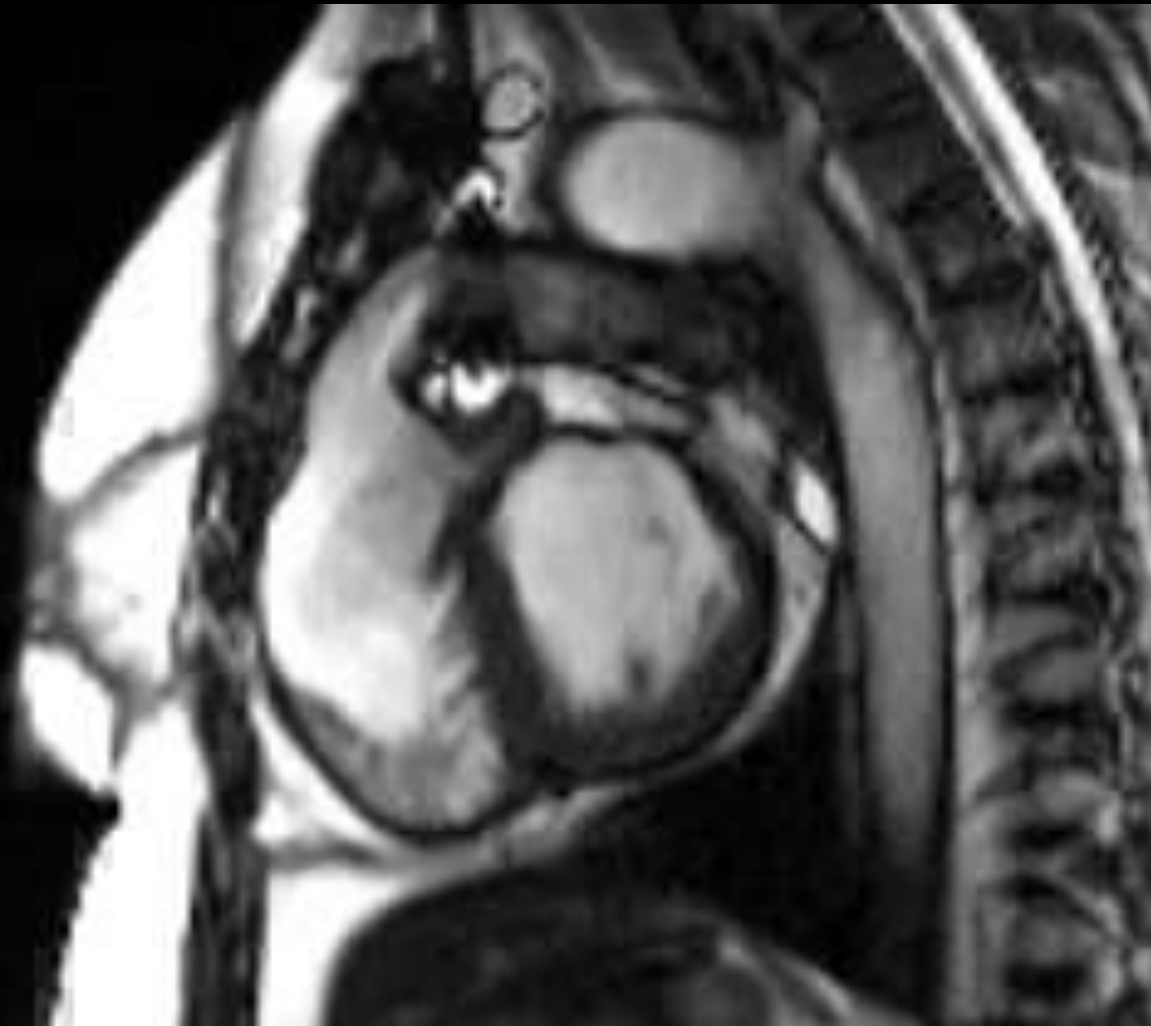
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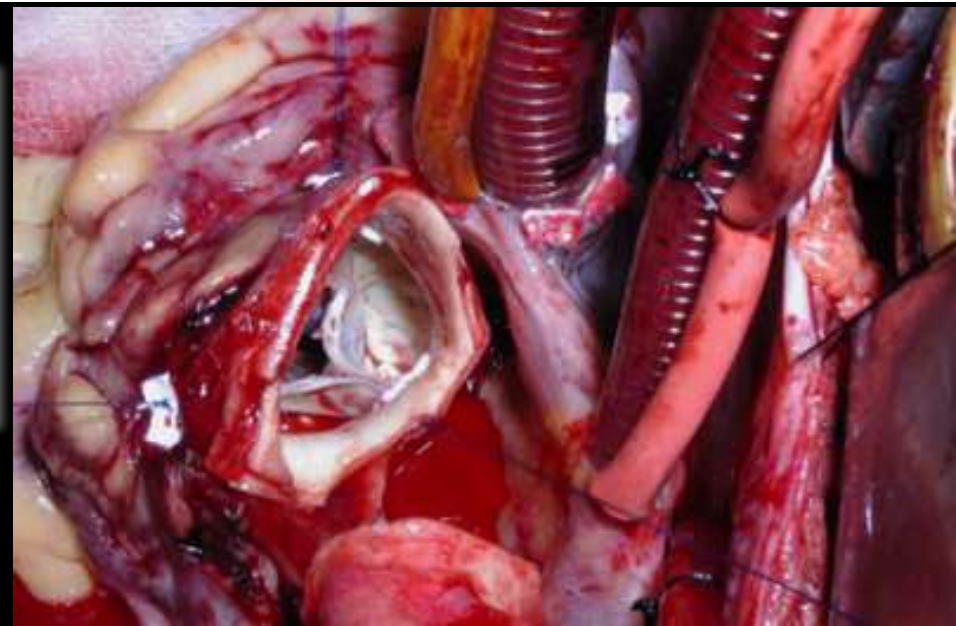
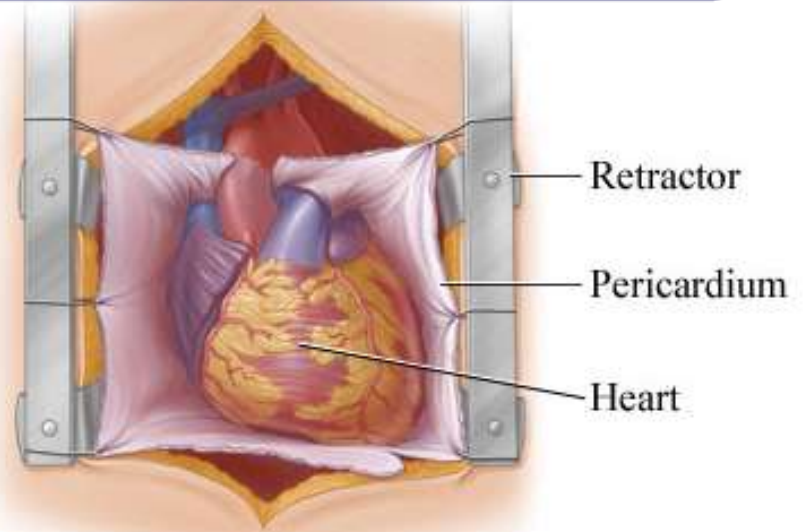
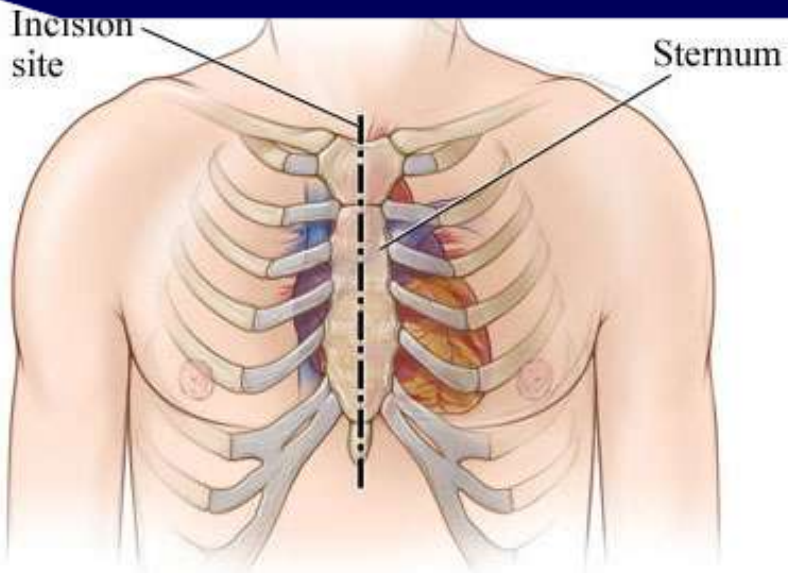
# Actuarial Probability of SCD-Free Survival After Surgical Treatment



# rTOF with Severe PI



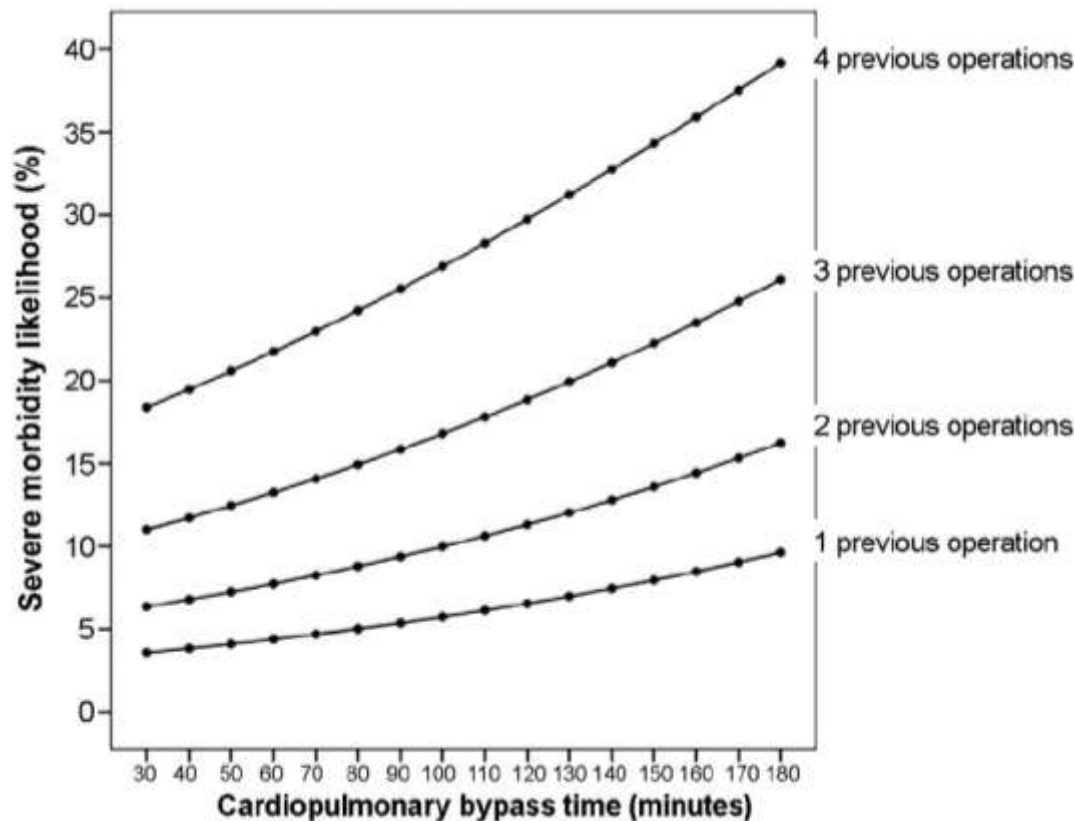
# OPEN HEART SURGERY



# Morbidity and Mortality Risk Factors in Adults With Congenital Heart Disease Undergoing Cardiac Reoperations

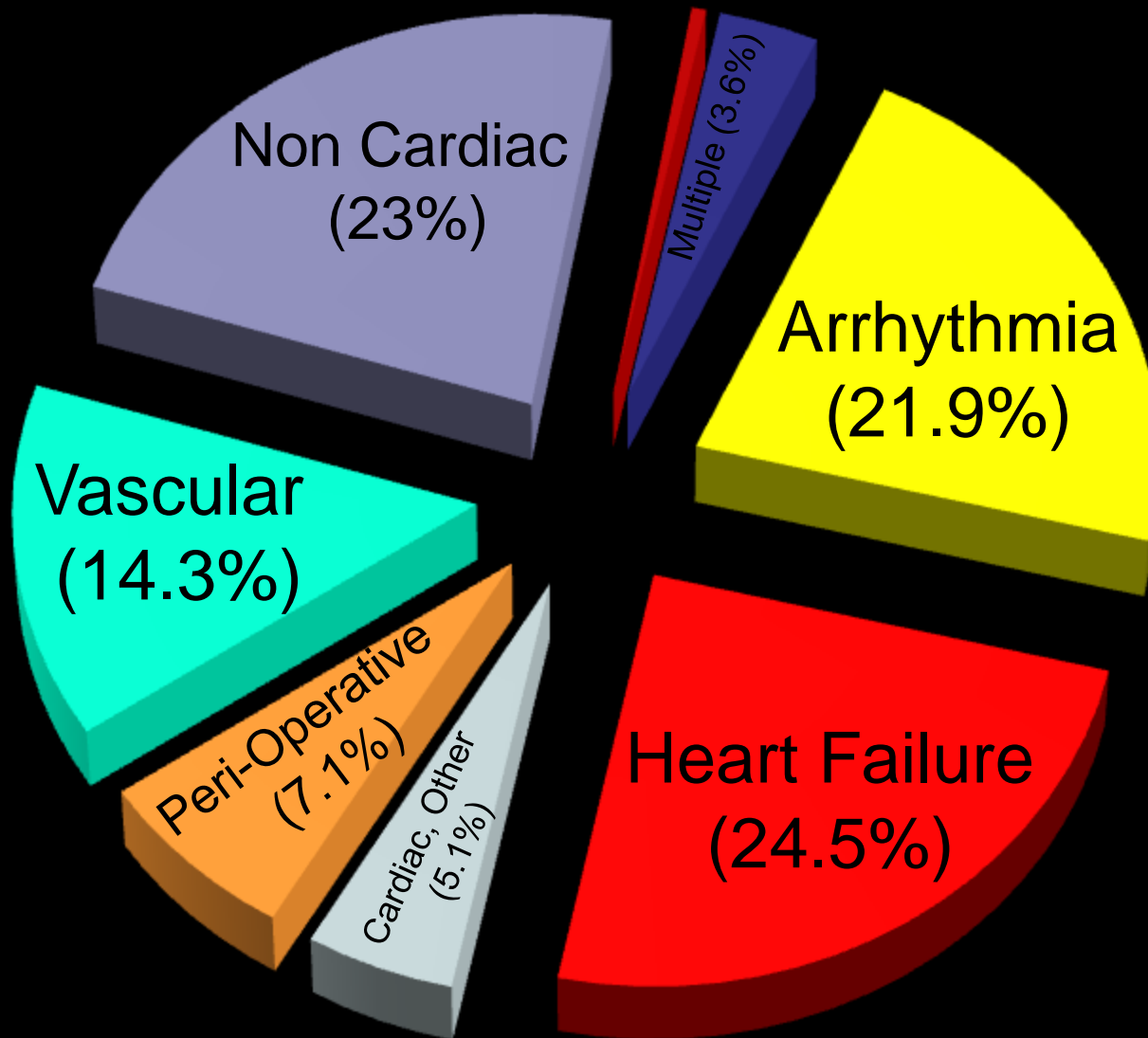
Alessandro Giamberti, MD, Massimo Chessa, MD, PhD, Raul Abella, MD, Gianfranco Butera, MD, Concetta Carlucci, MD, Halkawt Nuri, MD, Alessandro Frigiola, MD, and Marco Ranucci, MD

Department of Cardiac Surgery and Grown Up Congenital Heart Unit and Department of Cardiothoracic-Vascular Anesthesia and Intensive Care Unit, Istituto di Ricovero e Cura a Carattere Scientifico, Policlinico San Donato, San Donato Milanese, Milan, Italy



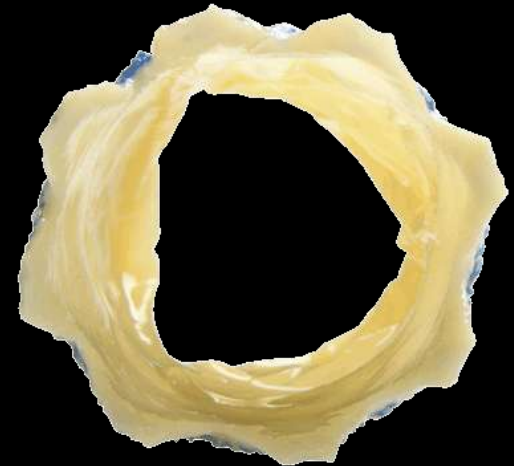
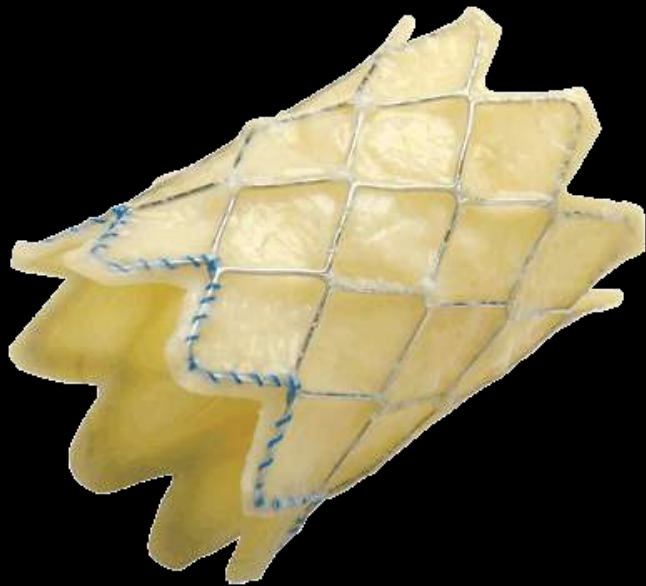
- 165 ACHD pts
- Morbidity/Mortality
- Severe Morbidity
  - Re-explore
  - Sternal wound infection
  - CVA
  - ARF
  - Prolonged Vent

# Cause of ACHD Mortality



# Melody Valve

- Bovine jugular venous valve segment
- Platinum-Iridium stent



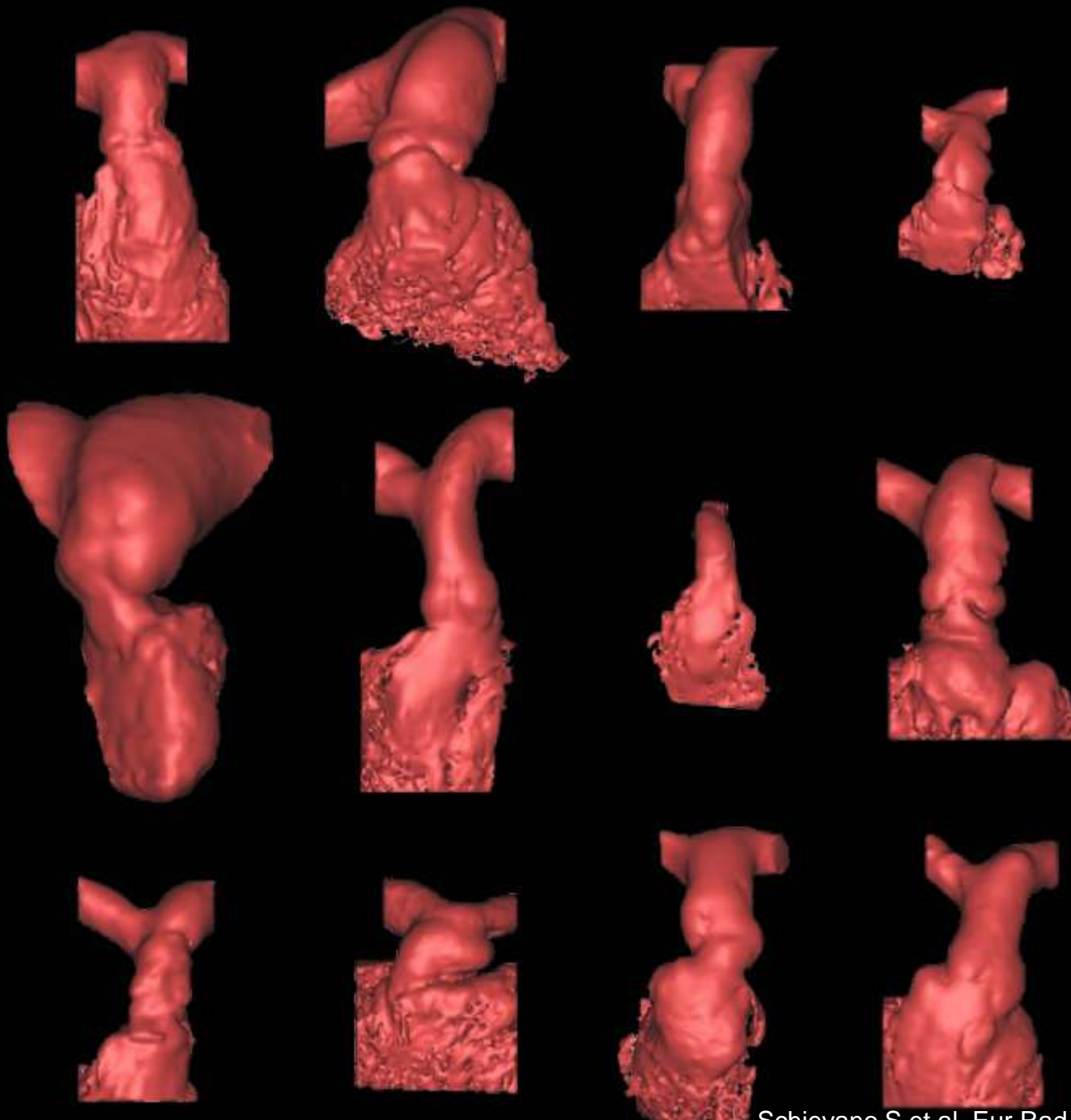
# 8 Zig- 34 mm Melody for PI

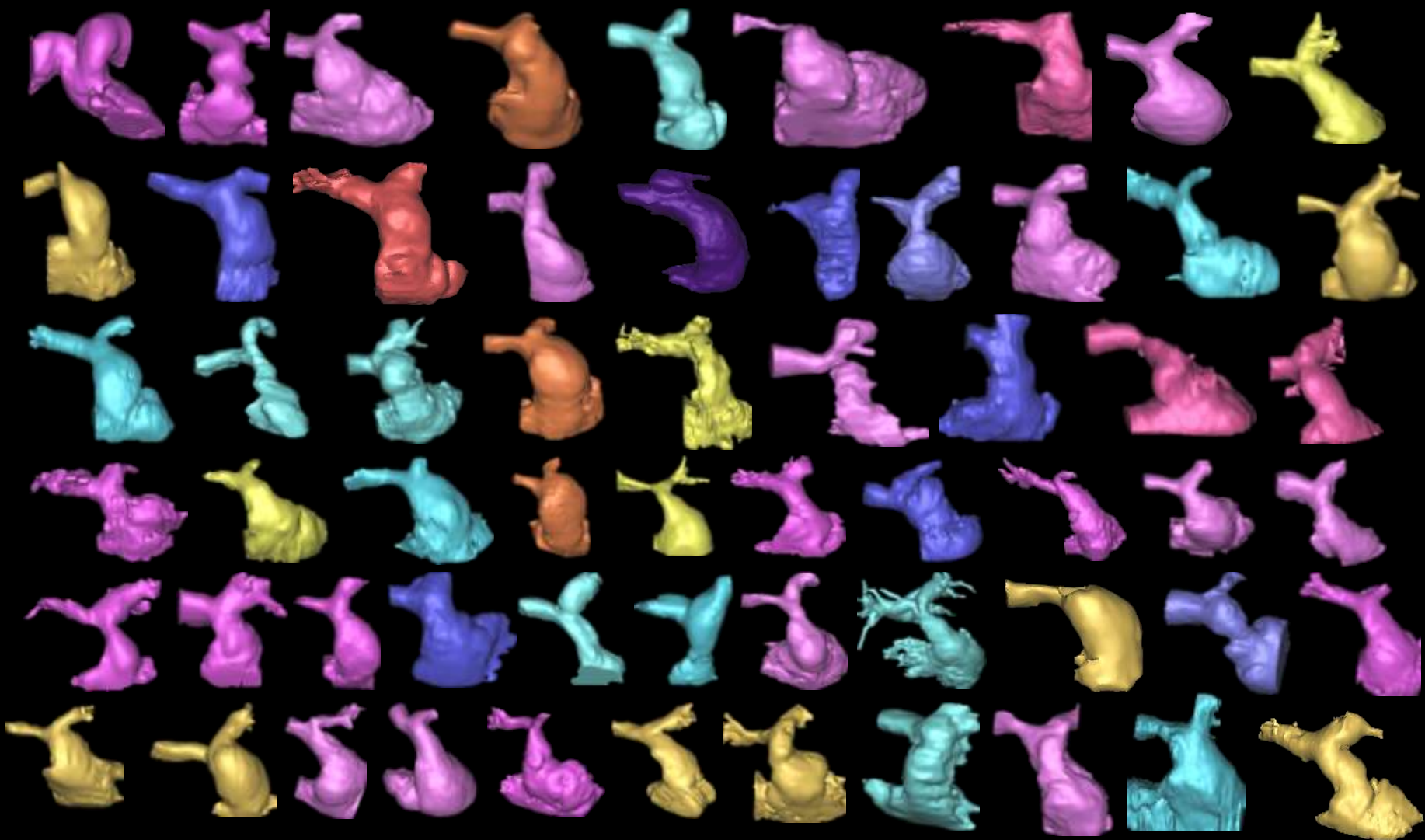


# TOF with Native RVOT Morphologic Variations

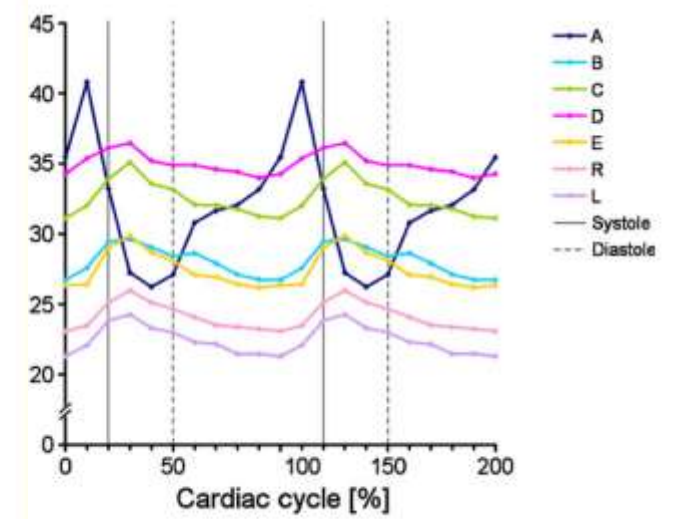
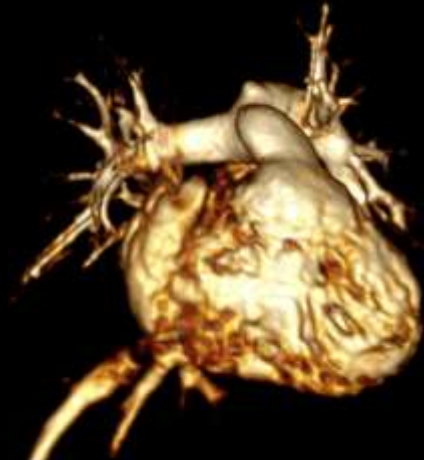
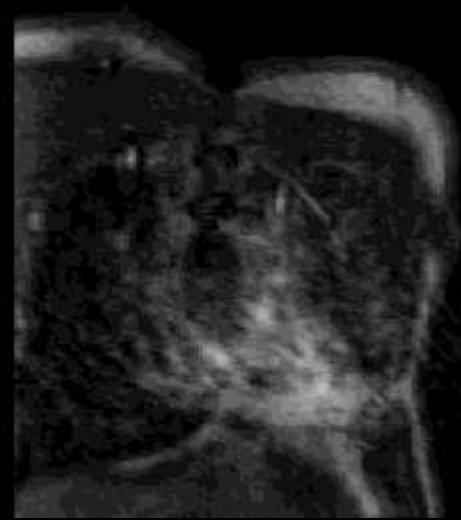
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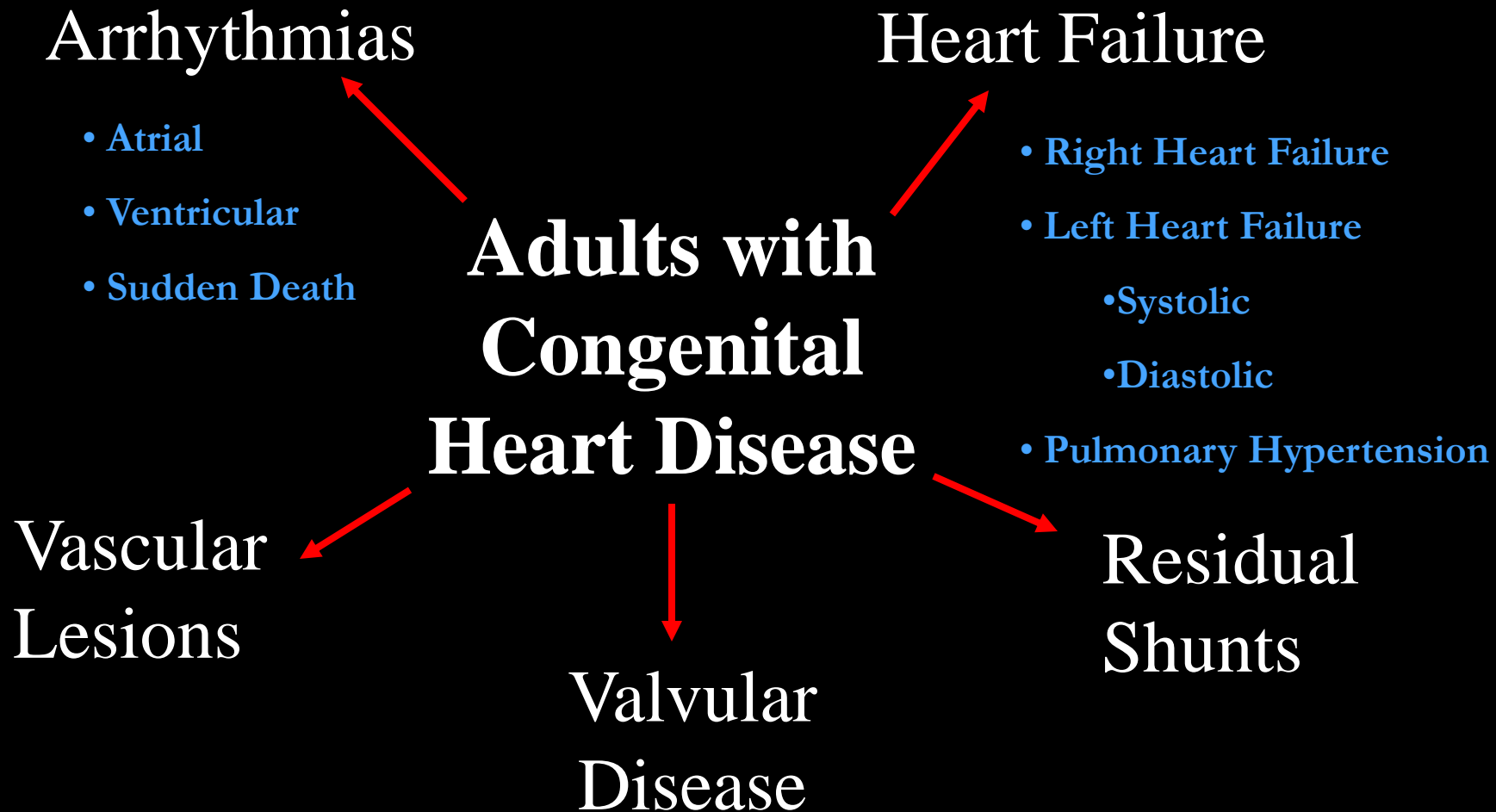


# Future of Valve Replacement

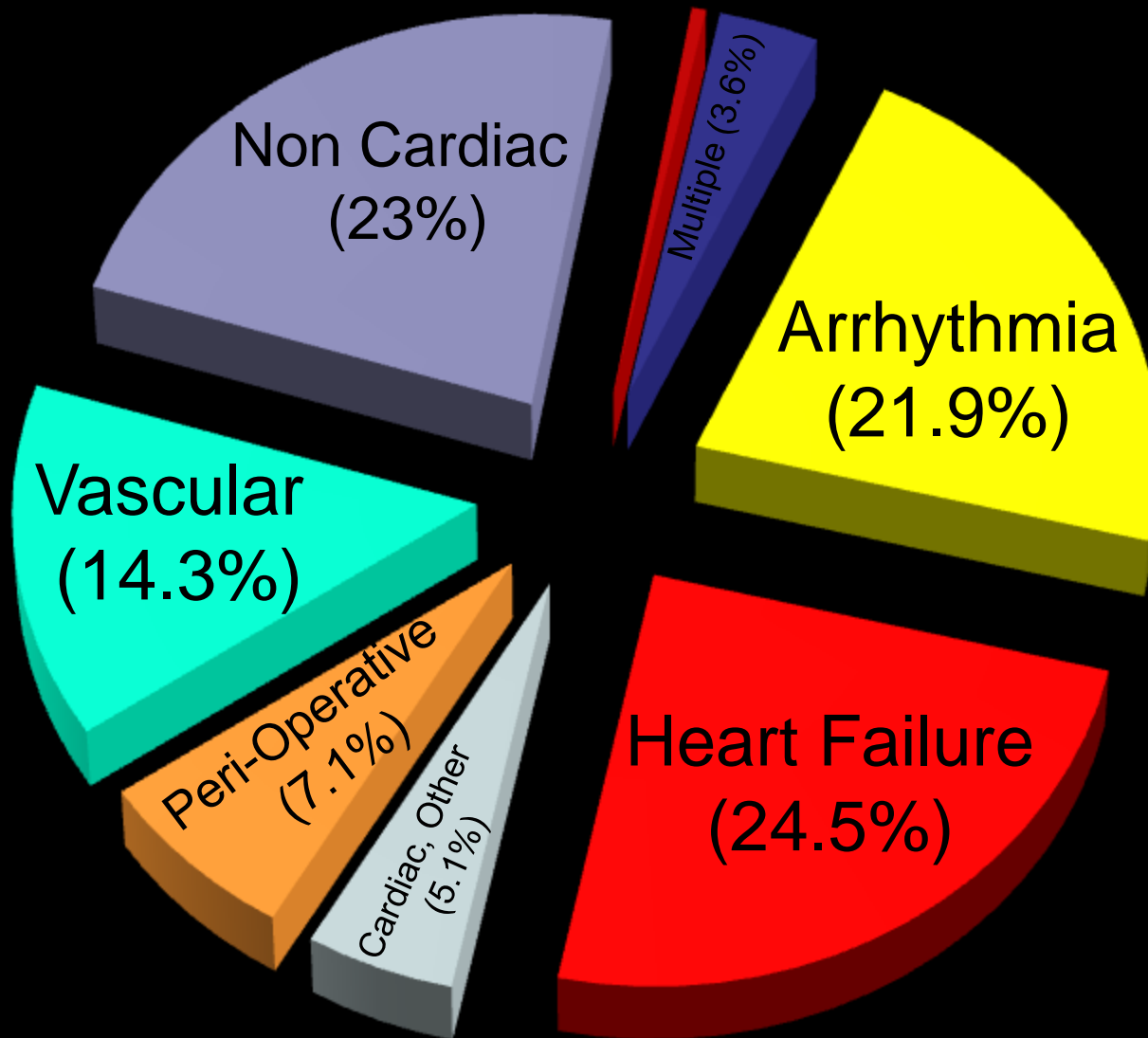


# Long –Term Complications

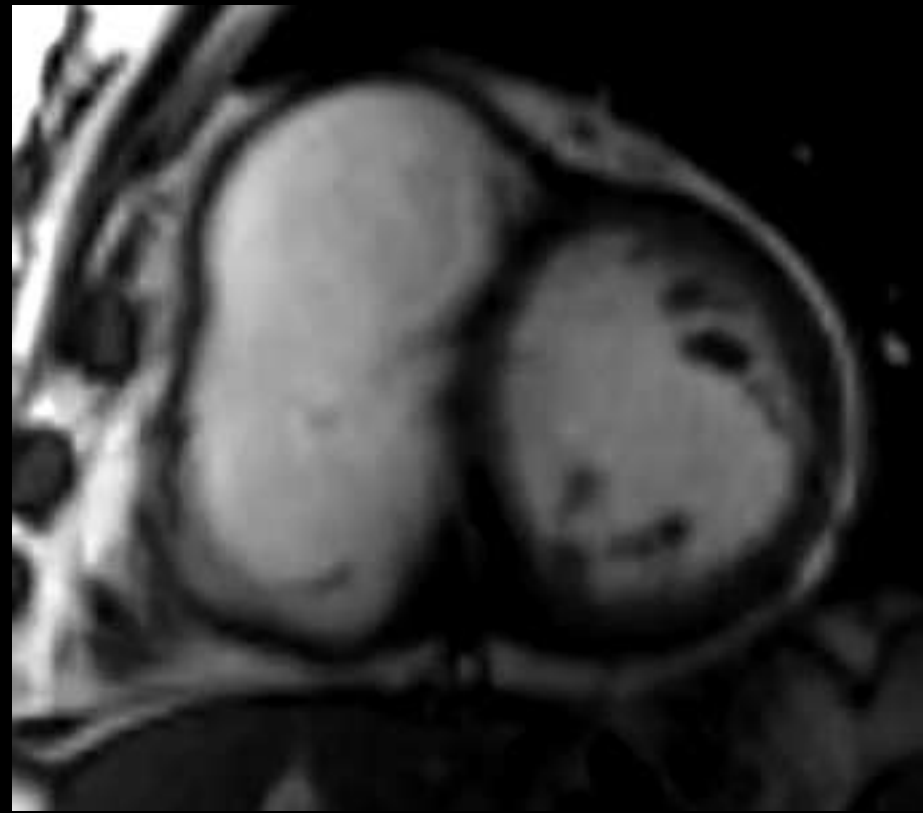
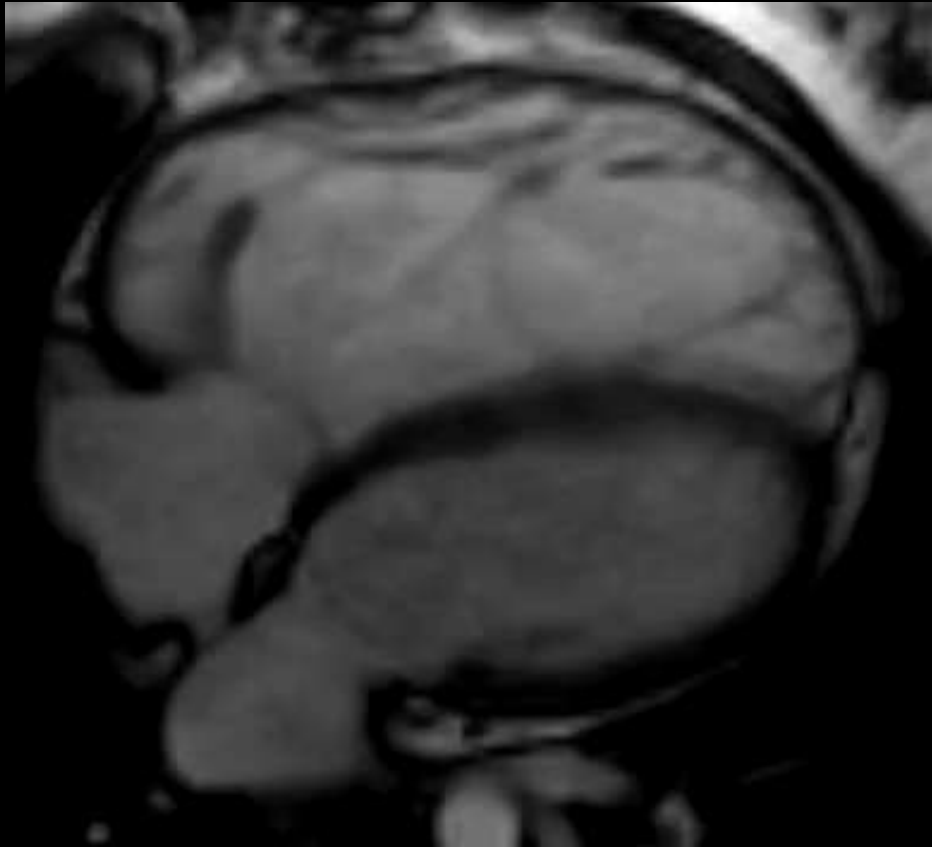
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# Cause of ACHD Mortality

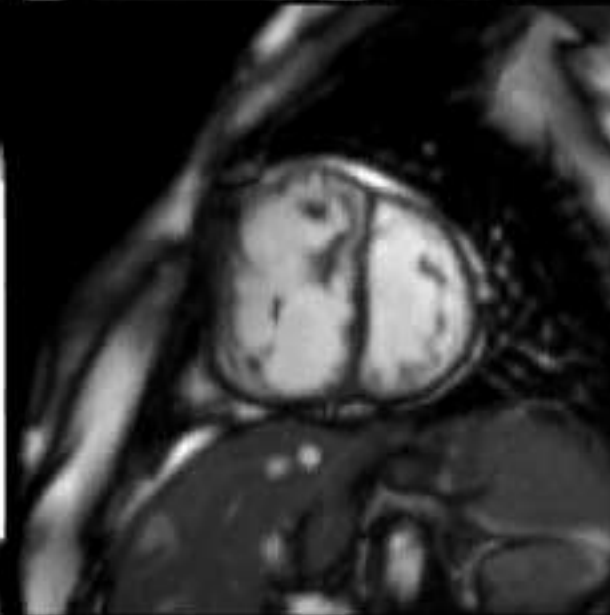
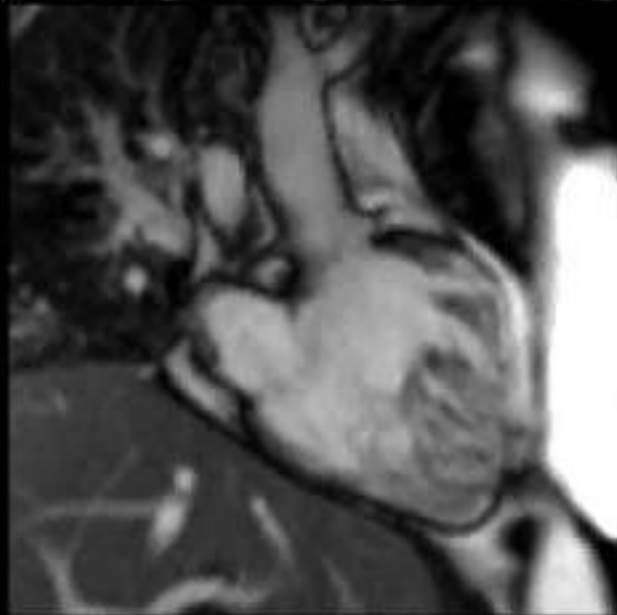


**26 yo Repaired TOF, Severe PI,  
RVEF 22 %**



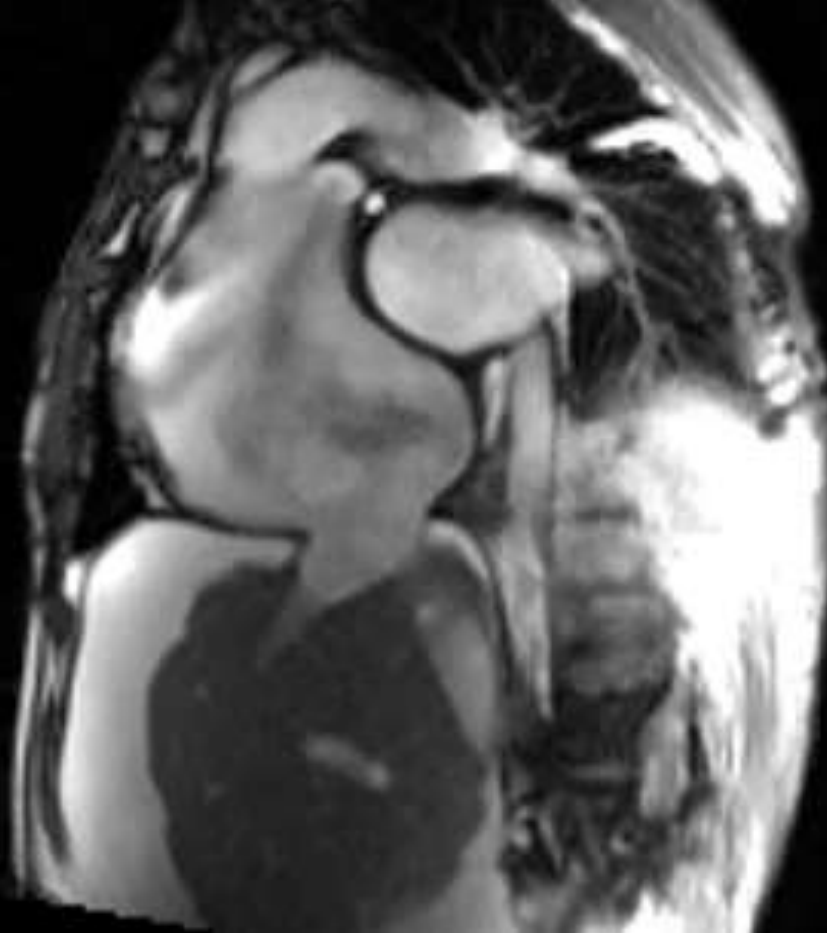
# 34 yo D-TGA/Atrial Switch

RVEF 32 %



# Single Ventricle Failing Fontan

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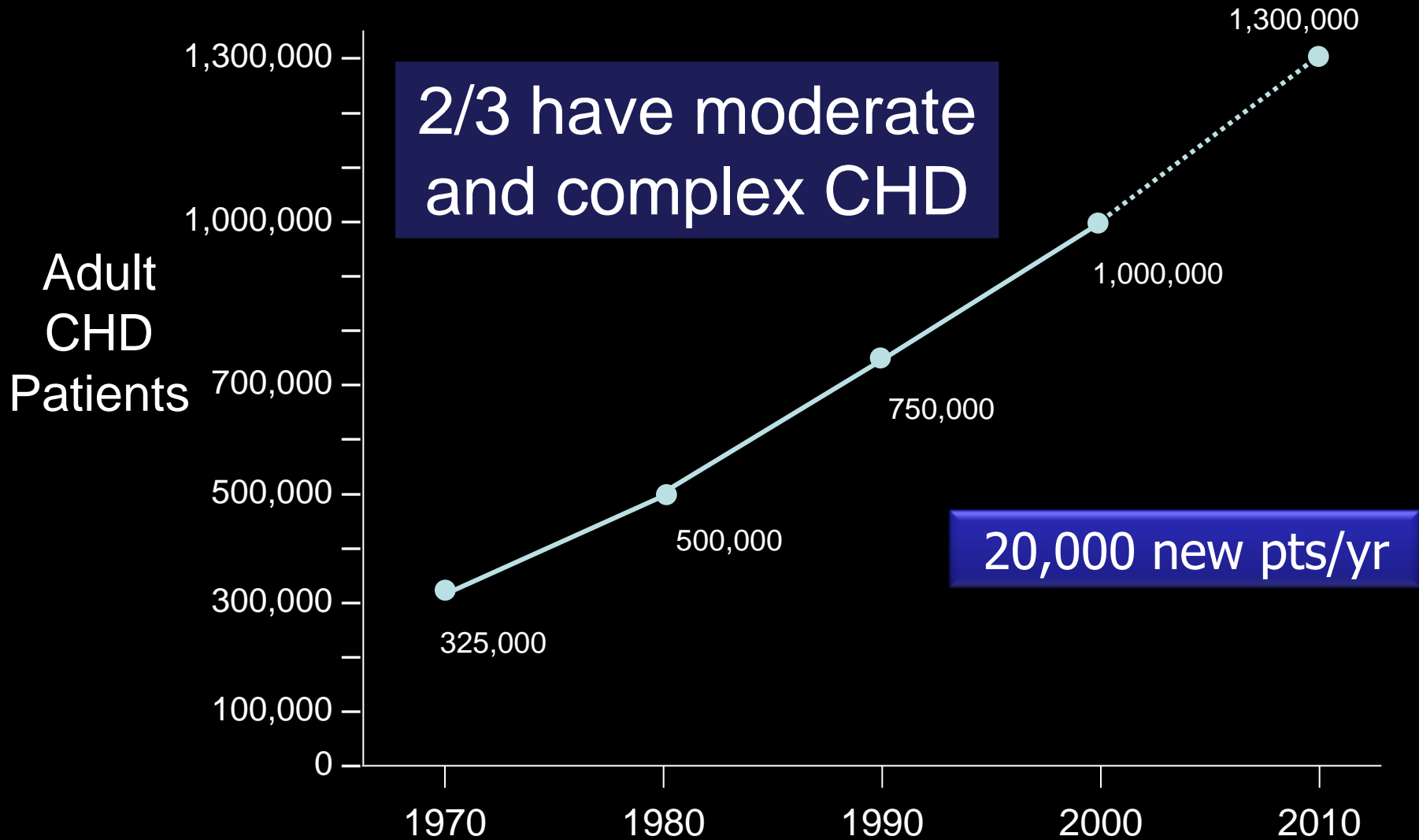


# ACHD – Heart Failure Trials

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0

# Patients Reaching Adulthood with CHD



**SOLUTION**

# Change The Outcome

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WHO takes care of the patients

- **How Do We Change  
The Outcome For  
ACHD Patients**

# ACHD Training

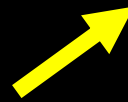
Residency

Cardiology

## Level 1: Basic Training for all Medical Cardiology Fellows

All medical cardiology trainees should be exposed to a core of information regarding adults with congenital heart disease. The goal of Level 1 training is for all graduates to be able to recognize and evaluate common, simple congenital heart lesions and the sequelae of the more commonly repaired congenital heart defects. These graduates should always consider consultation and collaborative patient management with a Level 2— or 3—trained specialist or pediatric cardiologist when major management decisions are made for adults with congenital heart disease and for periodic discussions of ongoing care.

We suggest that at least **6 hours of formal lectures** within the core curriculum of the training program be devoted to congenital heart disease in adults. Table 1 indicates the content suggested for these 6 hours, covering key basic and clinical aspects of these disorders.



General  
IM



Cardio  
IM

1

2

3

4

5

6

7

8

9

PGY



# ACHD Training

Residency

Cardiology

General  
PEDS



Cardio  
PEDS



General  
IM



Cardio  
IM

## LEVELS OF TRAINING

### Core Training (Level 1)

We differentiate three levels of training and expected expertise in the care of adults with CHD. Core training represents the level of knowledge appropriate for all trainees in pediatric cardiology and indicates the knowledge content that each graduate of such a program should acquire. This level of knowledge should be tested in the Subspecialty Certification Examination in Pediatric Cardiology and will provide the graduate with sufficient expertise to care for adolescents with CHD and prepare them for transition to ACHD care. In addition to the basic science and clinical knowledge included in every pediatric cardiology curriculum, certain additional knowledge areas should be included:

- general knowledge
- natural history of cardiac defects
- postoperative residua, long-term issues
- understanding care in the adult setting
- transition issues
- adolescent medicine
- outpatient experience
- lectures as part of core curriculum
- indications for and access to local/regional expert consultation
- adolescent and young adult medical care issues
- contraception, gynecologic issues, pregnancy
- physical activity, sports, and activity counseling
- education, health and general
- insurability
- employment
- psychosocial issues

1

2

3

4

5

6

7

8

9

PGY

**Petition for ACHD Subspecialty Certification  
American Board of Internal Medicine Pathway**

Based on ABIM Criteria for Recognition as Subspecialty  
Certification

**Michael J. Landzberg, MD and Curt Daniels, MD  
for the ABIM Petition Working Group**

**Member Representing  
Submitted in 2007**

Michael Landzberg, MD, FACC,  
Chair ISACHD

Curt Daniels, MD, FACC, Co-Chair ABP/ABIM

Elyse Foster, MD, FACC AHA

Thomas Graham, MD, FACC ABP

Gerard Martin, MD, FACC ACC

Stephanie Mitchell ACC

Amy Verstappen ACHA

Carole Warnes, MD, FACC ACC

Gary Webb, MD, FACC ACC/ACHA

# **Petition for ACHD subspecialty certification – American Board of Pediatrics**

**Based on ABP GUIDELINES FOR ESTABLISHING A NEW SUBSPECIALTY**

## **ABP Petition Writing Group**

### **Member**

### **Representing**

Thomas Graham, MD, FACC

ACC

Curt Daniels, MD, FACC

ACC

Robert Beekman, MD, FACC

AAP/JCCHD

Michelle Gurvitz, MD, FACC

ACC

Gerard Martin, MD, FACC

ACC/JCCHD

Allison Knauth, MD, FACC

AHA

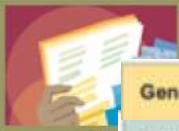
Catherine Webb, MD, FACC

JCCHD

David Sahn, MD, FACC

CHF

## News Release: ABMS Announces Certification in New Subspecialty Adult Congenital Heart Disease



### NEWS RELEASE

**ABMS Media Contact**  
**Lori Boukas**  
 (312) 436-2611  
[lboukas@abms.org](mailto:lboukas@abms.org)

[See complete list of specialty and subspecialty certificates](#)

### ABMS Announces Certification in New Subspecialty: Adult Congenital Heart Disease

**CHICAGO - December 5, 2012** - The American Board of Medical Specialties (ABMS) announces the creation of physician certification in a new subspecialty: Adult Congenital Heart Disease (ACHD). The ABMS Board of Directors and ABMS Reserved Powers Board approved the subspecialty at its September 2012 meeting. The subspecialty will be offered by the American Board of Internal Medicine (ABIM) and will create a pathway for certification for cardiologists previously certified by either the ABIM or the American Board of Pediatrics (ABP) with the expectation that the certification exam will be available within the next three years. The Accreditation Council for Graduate Medical Education (ACGME) will be approached to develop accreditation standards for training programs very shortly.

"Children who suffer from Pediatric Congenital Heart Disease are now surviving into adulthood, with specialized medical needs that will be best met by trained specialists in Adult Congenital Heart Disease noted Eric Holmboe, MD, FACP, ABIM's Chief Medical Officer. "This new subspecialty will enable patients to identify those clinicians with the competence and skill necessary to deliver quality care."

The ACHD subspecialty will:

- Meet the needs of the growing population of adults with congenital heart disease by ensuring there are enough physicians with the appropriate training to care for them in a consistent and comprehensive manner that is in compliance with recently published guidelines.
- Enable adult congenital heart specialists to work in an environment that specializes in caring for this patient population and provides a mechanism for transition of care from adolescence to adulthood that would eliminate gaps in medical care.
- Develop well-defined training pathways for internal and pediatric medicine cardiology trainees through the ABIM and the ABP. These pathways would culminate in a final common examination and subspecialty certification available.

General Certificate(s)	Subspecialty Certificates
American Board of Family Medicine	
Family Medicine	Adolescent Medicine Geriatric Medicine Hospice and Palliative Medicine Sleep Medicine Sports Medicine
American Board of Internal Medicine	
Internal Medicine	Adolescent Medicine <b>Adult Congenital Heart Disease<sup>3</sup></b> Advanced Heart Failure and Transplant Cardiology Cardiovascular Disease Clinical Cardiac Electrophysiology Critical Care Medicine Endocrinology, Diabetes and Metabolism Gastroenterology Geriatric Medicine Hematology Hospice and Palliative Medicine Infectious Disease Interventional Cardiology Medical Oncology Nephrology Pulmonary Disease Rheumatology Sleep Medicine Sports Medicine Transplant Hepatology
American Board of Medical Genetics	
Clinical Biochemical Genetics* Clinical Cytogenetics* Clinical Genetics (MD)* Clinical Molecular Genetics*	Medical Biochemical Genetics Molecular Genetic Pathology

# Change The Outcome

THE AMERICAN BOARD OF THORACIC SURGERY

## BOOKLET OF INFORMATION

### CONGENITAL HEART SURGERY SUBSPECIALTY CERTIFICATION

2012



Office of the Board  
633 North St. Clair Street, Suite 2320 Chicago, Illinois 60611  
(312) 202-5900  
[info@abts.org](mailto:info@abts.org)



American Board of Thoracic Surgery

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[Definition of Thoracic Surgery](#)

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[Instructions for Program Directors](#)  
[Part I \(Written\) Exam](#)  
[Part II \(Oral\) Exam](#)  
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[CHS MOC](#)

[Professional Portfolio](#)

[Programs](#)

[Program Directors Interface](#)  
[Annual Report](#)  
[Resident App Review](#)

[Residents](#)

[Residents OpLogs](#)

## CONGENITAL CARDIAC SURGERY SUBSPECIALTY CERTIFICATION

[HOME](#) >> [Congenital Cardiac Subspecialty](#)

Starting in 2009, the American Board of Thoracic Surgery offers a subspecialty certificate in Congenital Cardiac Surgery. Subspecialty Certification in Congenital Cardiac Surgery can be achieved by completing one of the following pathways and fulfillment of other requirements that are listed in the Congenital Cardiac Surgery Booklet of Information, which can be found on this web site.

**Pathway One** - Pathway One is the successful completion of a full congenital cardiac surgery residency approved by the ACGME, starting on July 1, 2008 or thereafter.

**Pathway Two** - Pathway Two is for those candidates who trained prior to July 1, 2008. Admission into the subspecialty certification process will be based on training, current clinical experience, and professional accomplishments in the field. Pathway II is available through the 2014 examination cycle.

The applications for the 2013 subspecialty certification process in Congenital Cardiac Surgery can be found in the box on the right-side of this page. The deadline for submitting an application is August 15 each year. Applications received after August 15 will automatically be deferred to next year.

The next Congenital Cardiac Surgery Part I (Written) will be held on December 2, 2013 at Pearson Testing Centers located throughout the United States.

#### BOOKLET OF INFORMATION

The 2013 Congenital Cardiac Surgery Booklet of Information is available by [Clicking Here](#).

#### APPLICATIONS

Applications for the 2013 Congenital Cardiac Surgery Subspecialty can be found below:

[2013 Application for Pathway I](#)

[2013 Application for Pathway II](#)

#### PATHWAY II EXTENSION

The Board has extended the deadline for candidates to apply for the Congenital Cardiac Surgery Subspecialty Exam via Pathway II (Grandfather Pathway) to 2014.

# Adults or Big Kids: What Is the Ideal Clinical Environment for Management of Grown-Up Patients With Congenital Heart Disease?

Tara Karamlou, MD, Brian S. Diggs, PhD, Ross M. Ungerleider, MD, MBA, and Karl F. Welke, MD, MS

Divisions of Cardiothoracic Surgery and Surgery, Oregon Health and Science University, Portland, Oregon; Division of Pediatric Cardiothoracic Surgery, Department of Surgery, Case Western Reserve University, Cleveland, Ohio; and Mary Bridge/Swedish Pediatric Cardiothoracic Surgery Program, Mary Bridge Children's Hospital and Health Center, Multicare Health System, Tacoma, Washington

*Background.* Initiatives to develop Adult Congenital Centers for management of grown-up congenital heart disease (GUCH) patients (aged  $\geq 18$  years) have widened without evidence identifying the ideal clinical environment. To elucidate the optimum care paradigm, we investigated whether mortality for patients with GUCH was influenced by the type of hospital where they had surgery, children's specialty hospital (CH) versus general hospital (GH), and by the clinical focus of the surgeon, congenital heart surgery (CHS) or noncongenital (adult acquired) heart surgery (NCHS).

*Methods.* In the Nationwide Inpatient Sample 1988–2003, we identified index procedures in patients 18 or more years of age within 12 congenital cardiac disease diagnostic groups. The CHS surgeons were defined as those whose annual practice volume consisted of more than 75% pediatric cardiac operations. Four clinical environment combinations were constructed: CH plus CHS, CH plus NCHS, GH plus CHS, and GH plus NCHS. Years were grouped into quartiles to identify trends in management over time.

*Results.* In all, 29,070 operations occurred at GH and 10,971 occurred at CH. Unadjusted in-hospital mortality was lowest in the CH plus CHS environment (1.14%),

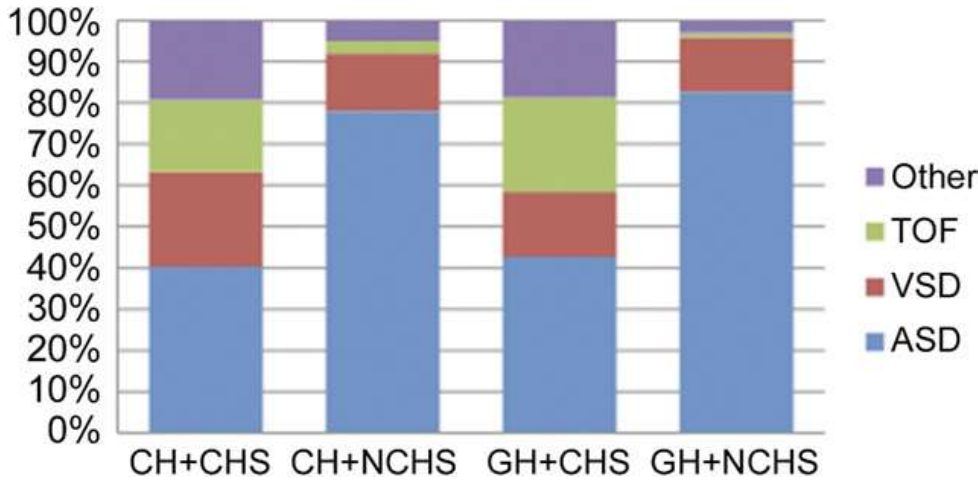
and highest for in the GH plus CHS environment (9.93%;  $p < 0.001$ ). After risk adjustment for patient factors, the CH plus CHS environment remained optimum, whereas the other three environments increased the risk of in-hospital death (GH plus NCHS: odds ratio 2.4 [95% confidence interval: 0.9 to 6.2]; CH plus NCHS: odds ratio 2.4 [95% confidence interval: 0.9 to 6.5]; GH plus CHS: odds ratio 9.1 [95% confidence interval: 3.0 to 27.6]). Over the study period, there was a dramatic rise in the number of GUCH patients treated in GH plus NCHS and CH plus NCHS, suggesting that the shift in clinical environment was provider specific rather than hospital-type specific.

*Conclusions.* Case mix varies with the clinical environment, with more complex procedures performed at GH plus CHS. The optimal environment for complex GUCH surgery involved CHS operating within CH. Initiatives to develop adult congenital centers dedicated to the care of GUCH patients are warranted, and should include congenital heart surgeons operating in a setting mimicking children's hospitals.

(Ann Thorac Surg 2010;90:573–9)

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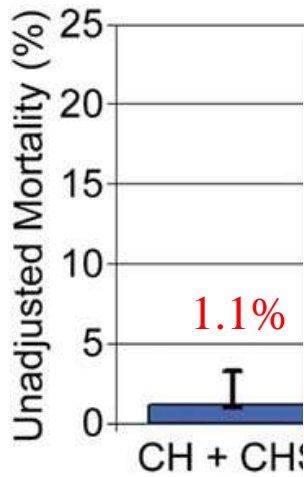
# al Clinical rown-Up ease?

ler, MD, MBA, and

Portland, Oregon; Division of Pediatric  
and, Ohio; and Mary Bridge/Swedish  
h Center, Multicare Health System,

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Centers for management of grown-up congenital heart  $p < 0.001$ . After risk adjustment for patient factors,



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Centers were grouped into management over time.

children's hospitals.

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(Ann Thorac Surg 2010;90:573-9)

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# Change The Outcome

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- ACHD Subspecialty Certification
- CHD Surgeons
- Multi-Center Research
- Evidence Based Clinical Guidelines

# Alliance for Adult Research in Congenital Cardiology (AARCC)

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University of Washington, Seattle, WA  
Oregon Health & Science Univ, Portland, OR  
University of California, Los Angeles, CA  
University of Colorado, Denver, CO  
Mayo Clinic, Rochester, MN  
Medical College of Wisconsin, Milwaukee, WI  
NCH/Ohio State University, Columbus, OH  
Pennsylvania State University, Hershey, PA  
University of Pennsylvania, Philadelphia, PA  
Columbia University, New York, NY  
Children's Hospital Boston, Boston, MA  
Montreal Heart Institute, Montreal, QC  
Baylor University, Houston TX  
Emory University, Atlanta, GA



**PRACTICE GUIDELINE: FULL TEXT**

## **ACC/AHA 2008 Guidelines for the Management of Adults With Congenital Heart Disease**

A Report of the American College of Cardiology/American Heart Association Task Force on Practice Guidelines (Writing Committee to Develop Guidelines on the Management of Adults With Congenital Heart Disease)

*Developed in Collaboration With the American Society of Echocardiography, Heart Rhythm Society, International Society for Adult Congenital Heart Disease, Society for Cardiovascular Angiography and Interventions, and Society of Thoracic Surgeons*

### WRITING COMMITTEE MEMBERS

Carole A. Wames, MD, FRCP, FACC, FAHA, Co-Chair; Roberta G. Williams, MD, MACC, FAHA, Co-Chair; Thomas M. Bashore, MD, FACC; John S. Child, MD, FACC, FAHA; Heidi M. Connolly, MD, FACC; Joseph A. Dearani, MD, FACC\*; Pedro del Nido, MD; James W. Fasules, MD, FACC; Thomas P. Graham, Jr, MD, FACC†; Ziyad M. Hijazi, MBBS, MPH, FACC, FSCAI‡; Sharon A. Hunt, MD, FACC, FAHA; Mary Etta King, MD, FACC, FASE§; Michael J. Landzberg, MD, FACC; Pamela D. Miner, RN, MN, NP; Martha J. Radford, MD, FACC;

**EXPERT OPINION**

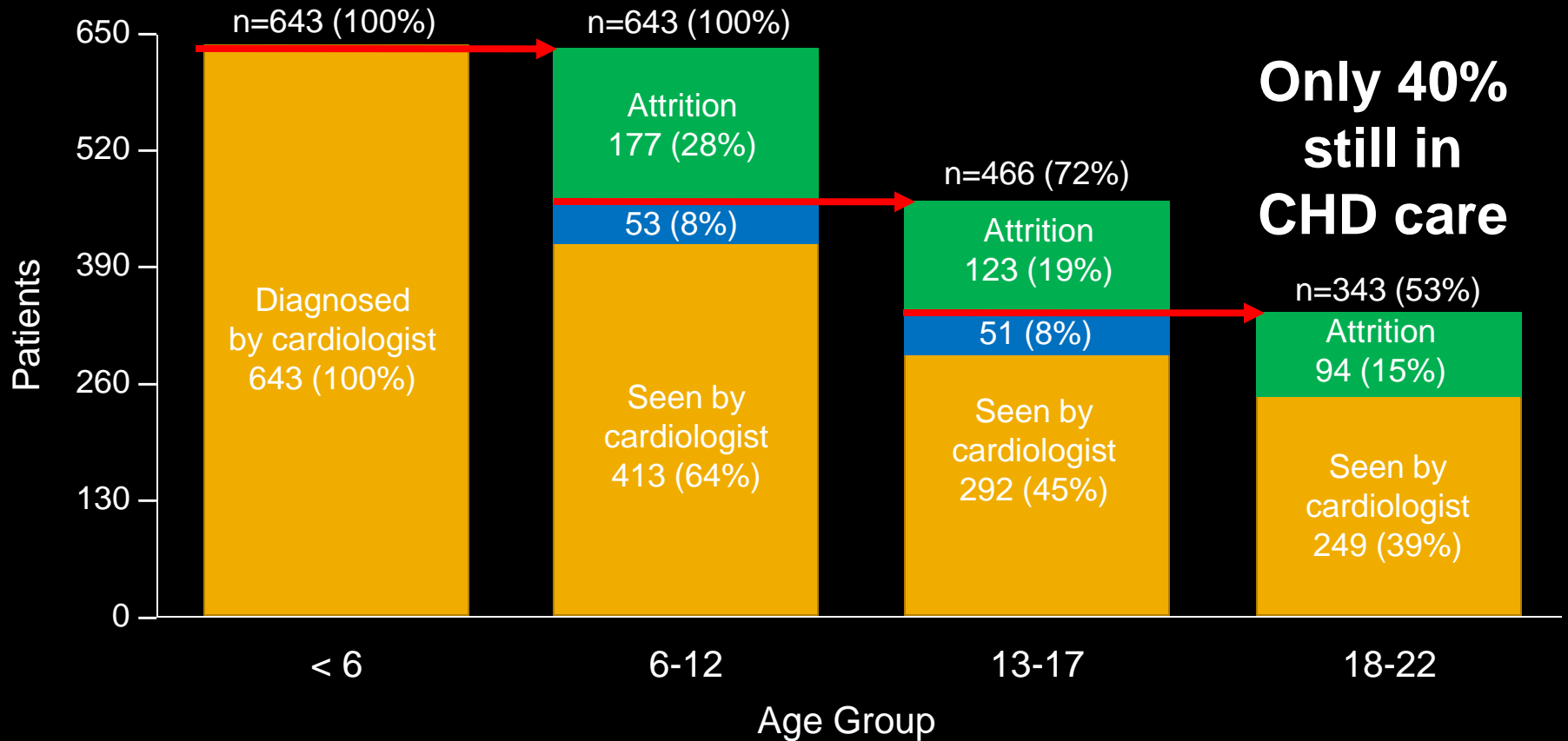
Sidney C. ... FAHA, Vice-Chair; Cynthia D. Adams, RSN, PhD, FAHA#; Jeffrey L. Anderson, MD, FACC, FAHA#; Elliott M. Antman, MD, FACC, FAHA\*\*; Christopher E. Buller, MD, FACC; Mark A. Creager, MD, FACC, FAHA; Steven M. Ettinger, MD, FACC; Jonathan L. Halperin, MD, FACC, FAHA#; Sharon A. Hunt, MD, FACC, FAHA#; Harlan M. Krumholz, MD, FACC, FAHA; Frederick G. Kushner, MD, FACC, FAHA; Bruce W. Lytle, MD, FACC, FAHA#; Rick A. Nishimura, MD, FACC, FAHA; Richard L. Page, MD, FACC, FAHA; Barbara Riegel, DNSc, RN, FAHA#; Lynn G. Tarkington, RN; Clyde W. Yancy, MD, FACC, FAHA

# Change The Outcome

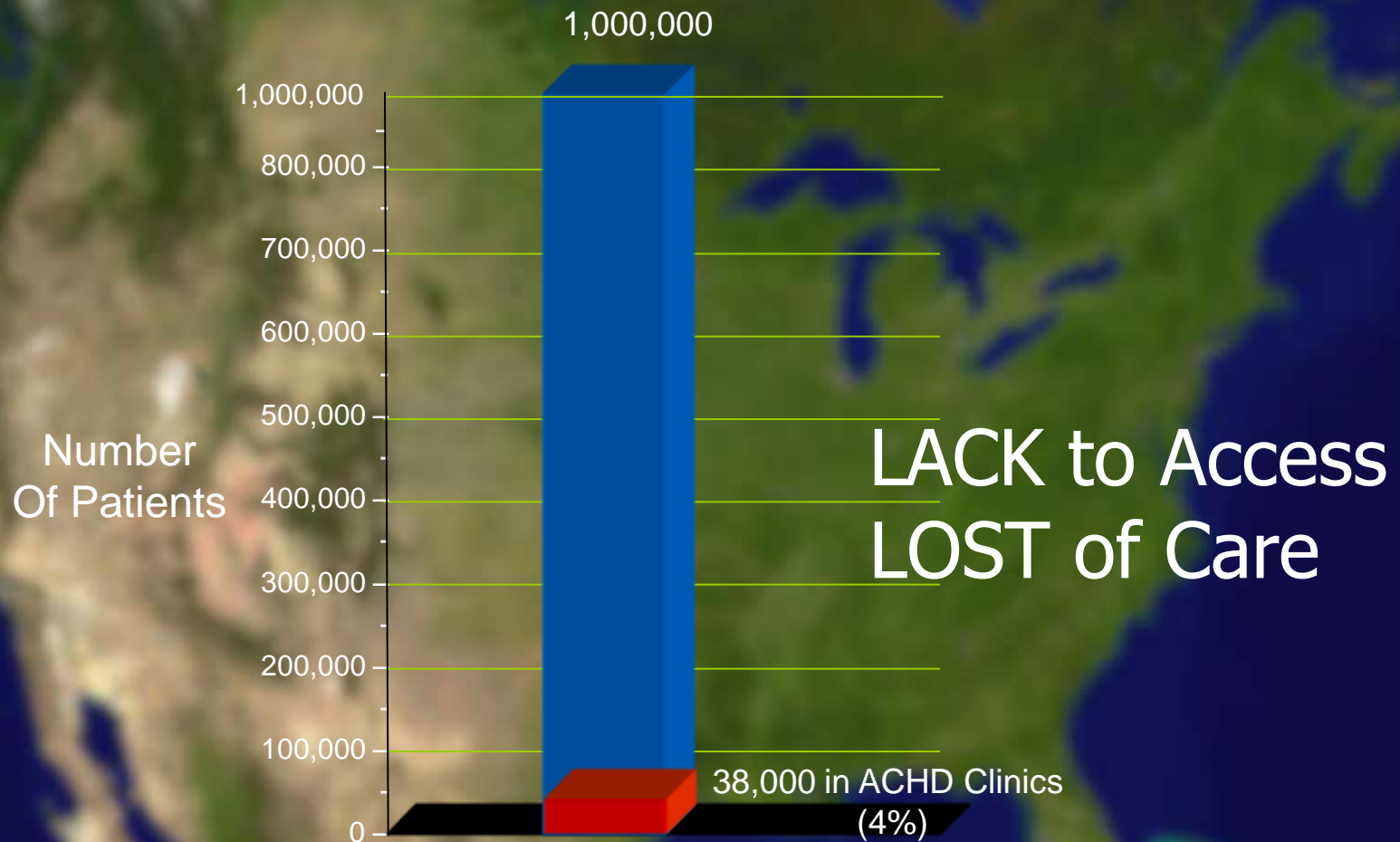
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- ACHD Subspecialty Certification
- CHD Surgeons
- Multi-Center Research
- Evidence Based Clinical Guidelines
- Reduce Lost to Care

# LOST TO CARE



# ACHD Patients in US vs Those in ACHD Clinics



Williams RG, et al. *J Am Coll Cardiol.* 2006;47(4):701-707.

ACHA Clinic Directory Working Group 2009

# Change The Outcome

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- ACHD Subspecialty Certification
- CHD Surgeons
- Multi-Center Research
- Evidence Based Clinical Guidelines
- Reduce Lost to Care
- ACHD Program Building

---

# Task Force 4: Organization of Delivery Systems for Adults With Congenital Heart Disease

Michael J. Landzberg, MD, FACC, *Co-Chair*, Daniel J. Murphy, JR, MD, FACC, *Co-Chair*, William R. Davidson, JR, MD, FACC, John A. Jarcho, MD, FACC, Harlan M. Krumholz, MD, FACC, John E. Mayer, JR, MD, FACC, Roger B. B. Mee, MD, ChB, David J. Sahn, MD, FACC, George F. Van Hare, MD, FACC, Gary D. Webb, MD, FACC, Roberta G. Williams, MD, FACC

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## RECOMMENDATIONS

- Care of adults with CHD should be coordinated by regional ACHD centers that represent a resource for the medical community.
- An individual primary caregiver or cardiologist without specific training and expertise in adult CHD should manage adults with moderate and complex CHD only in collaboration with a physician with advanced training and experience in caring for adults with CHD.
- Every academic adult cardiology/cardiac surgery center should have access to a regional ACHD center for consultation and referral.
- Every cardiologist should have a referral relationship with a regional ACHD center.
- Approximately one regional ACHD center should be created to serve a population of 5 to 10 million people, with 30 to 50 such centers in the U.S.
- Within a single urban center, institutions should establish collaborative relationships.
- Each pediatric cardiology program should identify the ACHD center to which the transfer of patients will be made.

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Chair

- Most cardiac catheterization and electrophysiology procedures for adults with moderate and complex CHD should be performed in a regional ACHD center with appropriate experience in CHD, and in a laboratory with appropriate personnel and equipment. After consultation with staff in regional ACHD centers, it may be appropriate for local centers to perform such procedures.
- Surgical procedures in adults with CHD as outlined in Tables 4 and 5 of Task Force #1 should generally be performed in a regional ACHD center with specific excellence in the surgical care of CHD.
- Each regional ACHD center should participate in a medical and surgical database aimed at defining and improving outcomes in adults with CHD.
- Each regional ACHD center should encourage all ACHD patient data to be included in a national CHD database. Programs should work collaboratively on multicenter projects and develop investigator-initiated research proposals dealing with ACHD.

## ACC/AHA 2008 Guidelines for the Management of Adults With Congenital Heart Disease: Executive Summary

### A Report of the American College of Cardiology/American Heart Association Task Force on Practice Guidelines (Writing Committee to Develop Guidelines for the Management of Adults With Congenital Heart Disease)

*Developed in Collaboration With the American Society of Echocardiography, Heart Rhythm Society, International Society for Adult Congenital Heart Disease, Society for Cardiovascular Angiography and Interventions, and Society of Thoracic Surgeons* (Circulation. 2008;118:2395-2451.)

#### 1.5. Recommendations for Delivery of Care and Ensuring Access

##### *Class I*

1. The focus of current healthcare access goals for ACHD patients should include the following:
  - a. **Strengthening organization of and access to transition clinics for adolescents and young adults with CHD, including funding of allied healthcare providers to provide infrastructure comparable to that provided for children with CHD. (Level of Evidence: C)**
  - b. **Organization of outreach and education programs for patients, their families, and caregivers to recapture patients leaving pediatric supervisory care or who are lost to follow-up. Such programs can determine when and where further intervention is required. (Level of Evidence: C)**
  - c. **Enhanced education of adult cardiovascular specialists and pediatric cardiologists in the pathophysiology and management of ACHD patients. (Level of Evidence: C)**
  - d. A liaison with regulatory agencies at the local, regional, state, and federal levels to create programs commensurate with the needs of this large cardiovascular population. (Level of Evidence: C)

2. **Health care for ACHD patients should be coordinated by regional ACHD centers of excellence that would serve as a resource for the surrounding medical community, affected individuals, and their families. (Table 2)**
  - a. **Every academic adult cardiology/cardiac surgery center should have access to a regional ACHD center for consultation and referral. (Level of Evidence: C)**
  - b. **Each pediatric cardiology program should identify the ACHD center to which the transfer of patients can be made. (Level of Evidence: C)**
  - c. All emergency care facilities should have an affiliation with a regional ACHD center. (Level of Evidence: C)
3. ACHD patients should carry a complete medical “passport” that outlines specifics of their past and current medical history, as well as contact information for immediate access to data and counsel from local and regional centers of excellence. (Level of Evidence: C)

# ACHD Delivery of Care

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- In the US, no standard for an delivery of ACHD care
- Extremes of what is called an “ACHD Program”

# ACHD CARE



## ACHD Clinic

- Director w No Formal ACHD training or experience
- No specialized APNs, RNs
- No ACHD call
- No CHD trained interv'alist, EP, surgical care
- No specialized ACHD outpt clinic
- No in-hospital ACHD consult svc
- No transition or patient education

## ACHD Program

- Director w ACHD training
- Specialized ACHD APNs, RNs
- 24/7 ACHD call
- Specific ACHD trained interventionalist, EP, surgery
- Specific ACHD outpatient
- ACHD hospital consult svc
- Advanced therapies
- Patient Education programs

# ACHA ACHD Program Accreditation

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**Goal:** To improve the quality of ACHD care delivered in the US.

## Objectives

- Establish minimal criteria for Accreditation of US ACHD Programs
- Incremental expansion of criteria with development of ACHD board certification, quality metrics, registry, database
- Application plus site visits
- Begin Accrediting Programs in 2015



# Change The Outcome

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- ACHD Subspecialty Certification
- CHD Surgeons
- Multi-Center Research
- Evidence Based Clinical Guidelines
- Reduce Lost to Care
- ACHD Program Building
- Accreditation and Quality Metrics
- Improve Communication and Education among Internal Medicine, Pediatric and ACHD cardiologists



# PATCH



**ACC Chapters Unite with the Adult Congenital Heart Association to Improve the Care for ACHD Patients:**

*Provider Action for Treating Congenital Hearts (PATCH)  
Pilot Program Chapter Opportunities*

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**ACC BOG and Chapters ↔ ACHA**

**The ACC/ACHA Provider Action for Treating Congenital Hearts (PATCH) Program:**

ACHA and ACC are working to collaborate on the PATCH Program to address four major challenges to the provision of high quality coordinated ACHD care in the U.S.:

- Lack of educational resources specific to the complex needs of the ACHD population
- Lack of awareness of ACHD care guidelines
- Access to ACHD trained cardiologists and centers of excellence
- Lack of networking between ACHD specialists and cardiologists



# PATCH



**ACC Chapters Unite with the Adult Congenital Heart Association to Improve the Care for ACHD Patients:**

*Provider Action for Treating Congenital Hearts (PATCH)  
Pilot Program Chapter Opportunities*

Internal  
Medicine  
Cardiology

ACHD  
Cardiology

Pediatric  
Cardiology





# PATCH



**ACC Chapters Unite with the Adult Congenital Heart Association to Improve the Care for ACHD Patients:**

*Provider Action for Treating Congenital Hearts (PATCH)  
Pilot Program Chapter Opportunities*

ACHD  
ACC Chapter  
Lecture

ACHD  
Webinars

ACHD  
Toolkit

Create  
Networking

# www.patchheartprogram.org



## About PATCH

ACHA AND ACC HAVE INITIATED THE PROVIDER ACTION FOR TREATING CONGENITAL HEARTS (PATCH), A PROGRAM INTENDED TO CREATE LEARNING OPPORTUNITIES AND COLLABORATION BETWEEN INTERNAL MEDICINE GENERAL CARDIOLOGISTS AND ADULT CONGENITAL HEART DISEASE SPECIALISTS.

The overarching goal of PATCH is to improve the care for adult congenital heart patients, and to do so through education, communication, and networking and by utilizing the organizational structure of ACHA, the ACC Board of Governors, Chapter infrastructure and its membership.

The ACC/ACHA PATCH Program will address four major challenges to the provision towards the highest quality coordinated ACHD care in the U.S.:

- Lack of educational resources specific to the complex needs of the ACHD population
- Lack of awareness of ACHD care guidelines
- Access to ACHD trained cardiologists and centers of excellence
- Lack of networking between ACHD specialists and internal medicine general cardiologists

For more information about the PATCH Program goals, please [click here](#).

There is a need for increased awareness of the ACC/AHA guidelines for ACHD care and when referral to ACHD provider is needed. [Click here](#) for more information about these guidelines.

- About PATCH
- CHD Information and Resources
- ACHD CME/CNE Activities
- CHD Societies and Organizations





## Provider Action for Treating Congenital Hearts (PATCH) Program Webinars

November 2012– May 2013

Date	Time	Webinar Subject/Title	Presenter
November 27, 2012	7-8 pm EST	ACHD 101 for the Healthcare Provider	Gary Webb, MD, FACC
December 10, 2012	7-8 pm EST	ASD: What every non-CHD Provider Should Know	Curt Daniels, MD, FACC
January 31, 2013	7-8 pm EST	CHD/PH Eisenmenger Syndrome	Michael Earing, MD, FACC
Date TBD	7-8 pm EST	Tetralogy of Fallot – The spectrum of late medical issues after repair	Joseph Kay, MD, FACC
February 13, 2013	7-8 pm EST	Discussing Pregnancy and Birth Control with your CHD Patients	Arwa Saidi, MD, FACC
March 2013	7-8 pm EDT	Transposition (D-TGA, L-TGA)	Alison Meadows, MD, PhD
April 2013	7-8 pm EDT	Single Ventricle/Fontan	Karen Stout, MD, FACC
May 2013	7-8 pm EDT	Bicuspid Aortic Valve/Coarctation	Stephen Cook, MD, FACC

All webinars are recorded and an archived version is available at [www.patchheartprogram.org](http://www.patchheartprogram.org).





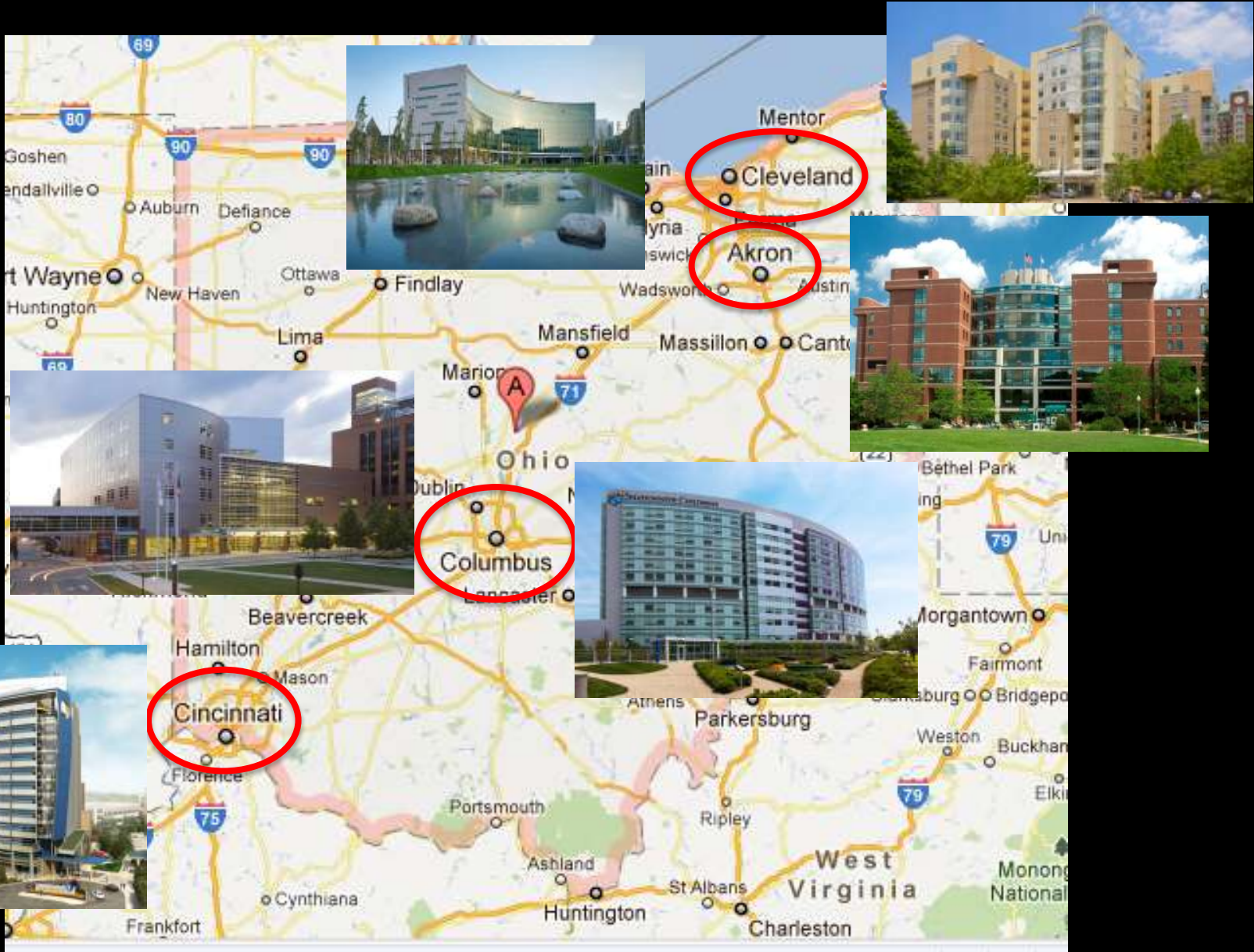
THE OHIO STATE UNIVERSITY MARCHING BAND

OHIO STATE

BUCKEYES

ACHD

# OHIO ACHD Programs



## Ohio Chapter of the American College of Cardiology Adult Congenital Heart Disease Resources

### AKRON

#### Adult Congenital Heart Service at Akron Children's Hospital

The Heart Center, Suite 5200  
One Perkins Square  
Akron OH 44308  
330-543-8521  
[www.akronchildrens.org](http://www.akronchildrens.org)

#### **Available presenter for local meetings:**

John R. Lane, MD  
Director of both Pediatric Cardiology and Adult Congenital Cardiology at Akron Children's Hospital

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### CLEVELAND

#### 1. Adult Congenital Heart Disease Services

##### The Cleveland Clinic

9500 Euclid Ave.  
Cleveland, Ohio 44195  
216-445-7430

#### **Available presenter for local meetings:**

Richard Krasuski, M.D. - [krasusr@ccf.org](mailto:krasusr@ccf.org)  
Director, Adult Congenital Heart Disease Services

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#### 2. UH Rainbow Babies & Children's Hospital

MS RBC 6001  
11100 Euclid Ave  
Cleveland, OH 44106  
216-844-8529  
Fax 216-844-5478

#### **Available presenter for local meetings:**

Christopher S. Snyder, MD  
[Christopher.snyder@uhhospitals.org](mailto:Christopher.snyder@uhhospitals.org)  
Associate Professor of Pediatrics  
Director, Division of Pediatric Cardiology  
KeyBank-Meyer Family Chair for Excellence in Leadership

### COLUMBUS

#### The COACH Program

Columbus Ohio Adult Congenital Heart Disease and Pulmonary Hypertension Program  
The Ohio State University  
Nationwide Children's Hospital  
700 Childrens Dr  
Columbus, OH 43205  
OSU: 614-293-8761  
NCH: 614-722-5622  
Director: Curt J. Daniels, MD, FACC, cell 614-204-8909

#### **Available presenters for local meetings:**

Curt J. Daniels, MD, FACC - [curt.daniels@osumc.edu](mailto:curt.daniels@osumc.edu)  
Ali Zaidi, MD - [ali.zaidi@osumc.edu](mailto:ali.zaidi@osumc.edu)  
Sharon Roble, MD, FACC - [sharon.roble@osumc.edu](mailto:sharon.roble@osumc.edu)

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### CINCINNATI

#### Cincinnati Adolescent and Adult Congenital Heart Disease Program

The Heart Institute at Cincinnati Children's Hospital Medical Center  
513-803-1777

#### **Available presenters for local meetings:**

Christopher Learn, MD - [christopher.learn@cchmc.org](mailto:christopher.learn@cchmc.org)  
Gruschen Veldtman, FRCP, MBChB - [gruschen.veldtman@cchmc.org](mailto:gruschen.veldtman@cchmc.org)  
Gary Webb, MD, FACC - [gary.webb@cchmc.org](mailto:gary.webb@cchmc.org)

# OHIO ACC SURVEY

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- 85% IM Cardiologist
- 50% Academic Cardiologist
- 46% Non-Invasive, 30% Invasive
- 46% in practice 10-20 years
- 62% See < 10, 30% 10-50 ACHD patients

\*Which statement best describes how you have learned to care for your ACHD pts?


Answer	0%	100%	Response Ratio
During my cardiovascular fellowship training			23.0 %
Articles and books when ACHD pts come through clinic			23.0 %
I call an ACHD specialist for help			38.4 %
I do not have a strategy and struggle to care for ACHD pts			15.3 %
No Response(s)			0.0 %
		Totals	100%

# OHIO ACC SURVEY

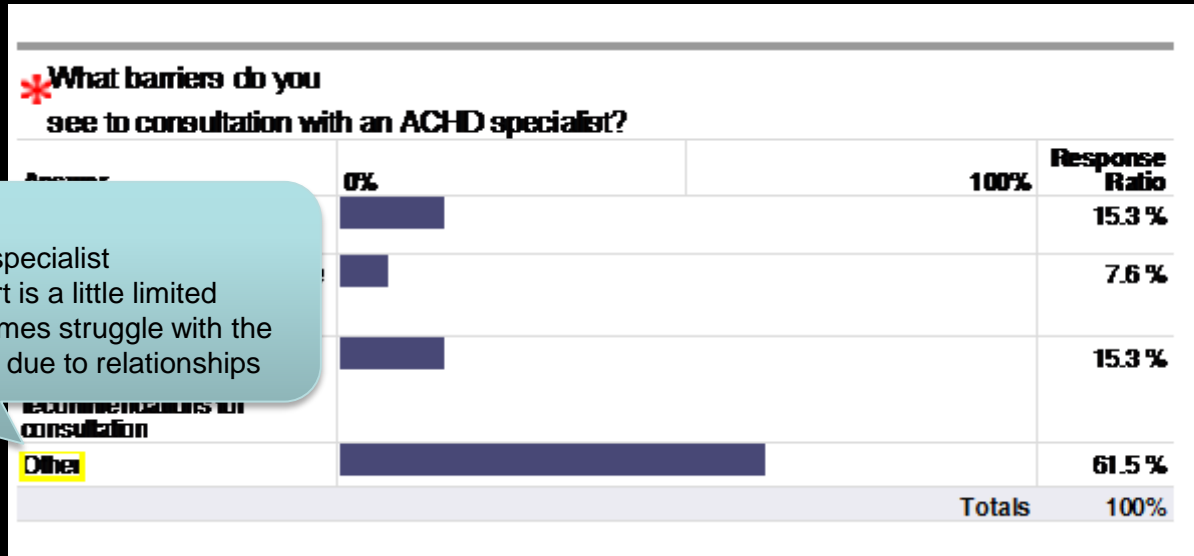
\*What resources would you like to have available to care for ACHD patients (only)

Answer	0%	100%	Response Ratio
Listing of local and regional ACHD specialists and contact information			76.9 %
Easy access to ACHD educational material and care guidelines			92.3 %
ACHD webinars			15.3 %
Regional ACHD conferences			30.7 %
Other			0.0 %
Totals			100%

\*Do you consult an ACHD specialist for patients with moderate and complex CHD

Answer	0%	100%	Response Ratio
Yes			100.0 %
No			0.0 %
No Response(s)			0.0 %
Totals			100%

# OHIO ACC SURVEY



## OTHER

1. Distance to specialist
2. Local support is a little limited
3. Patients at times struggle with the transfer of care due to relationships

## “Any other issues caring for ACHD patients?”

1. Complex patients at times prefer to stay locally in their community setting rather than travelling to the tertiary care centers that have ACHD specialists on staff.
2. Limited volumes make me feel uncomfortable caring for ACHD patients.
3. Where are they best cared for and what model is best? In other words, adult hospital versus pediatric hospital
4. Where are they best served for surgical or catheterization intervention?
5. Where are they best served for transplant?



# PATCH PANEL DISCUSSION

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- **Tim Feltes, MD, FACC**  
Chief of Pediatric Cardiology  
Nationwide Children's Hospital
- **Chris Learn, MD**  
ACHD Specialist  
Cincinnati Children's Hospital
- **Dave Orsinelli, MD, FACC**  
Academic Internal Medicine Cardiologist  
The Ohio State University
- **Michael Deucher, MD, FACC**  
Private Practice Internal Medicine Cardiologist  
Southwest General Health System Cleveland
- **Deena Barber, RN**  
ACHD Nurse Coordinator  
Akron Children's Hospital

# PATCH Program Resources

PATCH Program website [www.patchheartprogram.org](http://www.patchheartprogram.org)

American College of Cardiology [www.cardiosource.org](http://www.cardiosource.org)

Adult Congenital Heart Association [www.achaheart.org](http://www.achaheart.org)

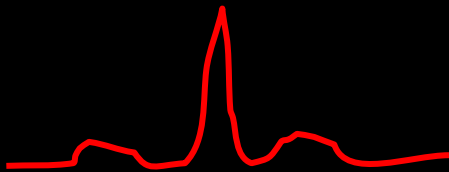
**ACHA/ISACHD Clinic Directory**

[www.achaheart.org/home/clinic-directory.aspx](http://www.achaheart.org/home/clinic-directory.aspx)



# Adult Congenital Heart Disease

Improving Education and Communication  
Among Cardiologist



Curt J Daniels, MD, FACC

Professor, Internal Medicine and Pediatrics

Director, **COACH** Program **C**olumbus **O**hio **A**dult **C**ongenital **H**ear Disease and  
Pulmonary Hypertension Programs

Division of Cardiology, The Ohio State University & The Heart Center at Nationwide  
Children's Hospital

