Adult Congenital Heart Disease

Improving Education and Communication Among Cardiologist

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

NATIONWIDE CHILDREN’S HOSPITAL

THE OHIO STATE UNIVERSITY

Medical Center
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
Survival to 18 yrs of age with CHD

Decade Born with CHD

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<td>Percent Survival to 18 Years Old</td>
<td>20%</td>
<td>40%</td>
<td>75%</td>
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ACHD - Population

Surviving to Adulthood is Now Expected
Congenital Heart Disease Population

- **70%** Pediatric
- **30%** Adult

1965

Congenital Heart Disease Population

50% PEDIATRIC
50% ADULT

2000

Congenital Heart Disease Population

- 40% PEDIATRIC
- 60% ADULT

2010

Adult vs Pediatric Complex CHD Populations in Canada

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

More Adults Than Children with CHD

2/3 have moderate and complex CHD

20,000 new pts/yr
PROBLEM
Patients Reaching Adulthood with CHD

Adult CHD Patients

- 1970: 325,000
- 1980: 500,000
- 1990: 750,000
- 2000: 1,000,000
- 2010: 1,300,000

20,000 new pts/yr
Actuarial Probability of SCD-Free Survival After Surgical Treatment

Mortality in adult congenital heart disease

Carianne L. Verheugt1,2,3, Cuno S.P.M. Uiterwaal1, Enno T. van der Velde4, Folkert J. Meijboom5, Petronella H. van Dijk7, Hubert W. Vliegen4, Diederick E. Grobbee1, and Erik Zwinderman6

1Julius Center for Health Sciences and Primary Care, University Medical Center Utrecht, The Netherlands; 2Interuniversity Cardiology Institute of the Netherlands; 3Department of Cardiology, Academic Medical Center, Amsterdam, The Netherlands; 4Department of Cardiology, Leiden University Medical Center, Leiden, The Netherlands; 5Department of Cardiology, University Medical Center Groningen, Groningen, The Netherlands; 6Department of Cardiology, St Antonius Hospital, Nijmegen, The Netherlands; 7Department of Cardiology, University Medical Center Utrecht, Room B2-240, The Netherlands

Non Cardiac (23%)
Arrhythmia (21.9%)
Vascular (14.3%)
Peri-Operative (7.1%)
Cardiac, Other (5.1%)
Multiple (3.6%)

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

Mean Age of Death < 30 yrs

Verheugt CL et al. EHJ 2010.31:1220-29.
Age at Death for Adults with CHD

- Tricuspid Atresia: 27 ± 5
- TGV: 27 ± 7
- COA: 29 ± 6


n = 2609 patients
199 died
Mean age for all dx 37 ± 15 years
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
Hospital Admission Rate
General Population vs ACHD

Admission Rate (%)

Age Groups (years)

20-30 30-40 40-50 50-60 60-70 70-80

General population
ACHD population

Verheugt CL et al. Heart 2010. 96:872-78
MORBIDITY

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

Rate of ACHD admissions > 2X Pediatric CHD admissions since 1998

Error bars represent 95% CIs.

Rate of ACHD admissions almost 3X (Cardiology Unit) 8X (ICU) Since 2007
Once Reaching ACHD

- Survival is not as expected
- HF and arrhythmia (~ 45%)
- Morbidity is substantial
Long – Term Complications

Adult Co-Morbidities

- CAD, PVD
- DM
- OSA, COPD
- Renal and Hepatic Insufficiency

- Atrial
- Ventricular
- Sudden Death

- Right Heart Failure
- Left Heart Failure
- Systolic
- Diastolic
- Pulmonary Hypertension

- Residual Shunts

- CAD, PVD
- DM
- OSA, COPD
- Renal and Hepatic Insufficiency

- Atrial
- Ventricular
- Sudden Death

- Right Heart Failure
- Left Heart Failure
- Systolic
- Diastolic
- Pulmonary Hypertension

- Residual Shunts
38 yo with TOF s/p repair, DM, presents with chest pain
Long –Term Complications

Arrhythmias
- Atrial
- Ventricular
- Sudden Death

Heart Failure
- Right Heart Failure
- Left Heart Failure
  - Systolic
  - Diastolic
  - Pulmonary Hypertension

Vascular Lesions

Valvular Disease

Residual Shunts

Adults with Congenital Heart Disease
Prevalence of Arrhythmias in ACHD Patients


### Main Diagnosis

- Fallot
- TGA
- Aortic Stenosis
- Pulmonary Stenosis
- ASD
- ASD I
- Aortic Coarctation
- Fontan

### Prevalence of Arrhythmias (%)

- Supraventricular (%)
- Ventricular (%)

**n = 5,790**
Cumulative Risk of Atrial Arrhythmia in ACHD

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

20 year old with CHD
AA risk equivalent to
55 year old without CHD

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

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

Mortality ↑50%
Stroke ↑50%
CHF ↑2.5x
Single Ventricle/Fontan

Modified Fontan

Lateral Tunnel
Single Ventricle/Fontan
Single Ventricle/Fontan

Holter monitor

P waves

5 second pause
25 yo with D-TGA/Mustard syncope while driving – admitted to local hospital
The patient presents with palpitations and near syncope. The ECG shows:

**Event Summary**

1. **Rec: 06/01/2013 02:32 PM**
   - Sinus Rhythm w/ PVC(1)/Lead Loss
   - 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 AM**
   - Sinus Rhythm w/ 10 Beats Of V-Tach/ PVCs (5)
   - Symptom: Auto Detect- Racing Heart
   - 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
   - Type: Patient-Activated
   - Transmitted 06/15/2013 10:07 PM
   - HR: 98.8-102.2 BPM
   - Comments: Patient Activated
   - Tech: Jose John

The ECG shows 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.
D-TGA/Atrial Switch

Diagram showing the anatomy of the heart with labels for SVC, SVB, Ao, MPA, PV, RV, and LV.
SVC Baffle Obstruction
24 yo D-TGA/Mustard referred after unable to place pacer wire
24 yo D-TGA – Mustard
D-TGA/Atrial Switch

SVC

IVC
24 yo D-TGA/Atrial Switch with SVC Obstruction
43 yo with rTOF x 4, doing well until syncopal spell, presents with
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 (≥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 ± 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

Arrhythmias
- Atrial
- Ventricular
- Sudden Death

Heart Failure
- Right Heart Failure
- Left Heart Failure
  - Systolic
  - Diastolic
  - Pulmonary Hypertension

Vascular Lesions

Adults with Congenital Heart Disease

Valvular Disease

Residual Shunts
COA
Coarctation of the Aorta - Surgery

A. 
B. 
C. 
D. 
E.
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

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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)*
34 yo female rCOA, HTN X 14 yrs LVEF 20%
Usefulness of Screening Cardiovascular Magnetic Resonance Imaging to Detect Aortic Abnormalities After Repair of Coarctation of the Aorta

Shane F. Tsai, MD\textsuperscript{a,b,*}, Mira Trivedi\textsuperscript{b}, Bethany Boettner, MA\textsuperscript{c}, and Curt J. Daniels, MD\textsuperscript{a,b}

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 ± 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 ≤0.5 (at risk ≤0.75), ascending aorta aneurysm as maximum ascending cross-sectional area/height ≥10 (at risk ≥5), and descending aorta aneurysm as maximum descending diameter/descending aorta at the diaphragm ≥1.5 (at risk ≥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
Long–Term Complications

Adults with Congenital Heart Disease

Arrhythmias
- Atrial
- Ventricular
- Sudden Death

Heart Failure
- Right Heart Failure
- Left Heart Failure
  - Systolic
  - Diastolic
  - Pulmonary Hypertension

Residual Shunts

Vascular Lesions

Valvular Disease
rTOF
Actuarial Probability of SCD-Free Survival After Surgical Treatment

SCD-Free Survival (proportion)

Postoperative Interval (years)

n = 3589

rTOF with Severe PI
OPEN HEART SURGERY

Incision site

Sternum

Retractor

Pericardium

Heart
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

- Non Cardiac (23%)
- Arrhythmia (21.9%)
- Vascular (14.3%)
- Peri-Operative (7.1%)
- Cardiac, Other (5.1%)
- Other (3.6%)

Verheugt CL et al. EHJ 2010.31:1220-29.
Melody Valve

- Bovine jugular venous valve segment
- Platinum-Iridium stent
TOF with Native RVOT Morphologic Variations
Future of Valve Replacement
Long–Term Complications

**Arrhythmias**
- Atrial
- Ventricular
- Sudden Death

**Heart Failure**
- Right Heart Failure
- Left Heart Failure
  - Systolic
  - Diastolic
- Pulmonary Hypertension

**Residual Shunts**

**Vascular Lesions**

**Valvular Disease**

**Adults with Congenital Heart Disease**
Cause of ACHD Mortality

- Non Cardiac (23%)
- Arrhythmia (21.9%)
- Heart Failure (24.5%)
- Vascular (14.3%)
- Peri-Operative (7.1%)
- Cardiac, Other (5.1%)
- Multiple (3.6%)

26 yo Repaired TOF, Severe PI, RVEF 22 %
34 yo D-TGA/Atrial Switch

RVEF 32 %
Single Ventricle Failing Fontan
ACHD – Heart Failure Trials
Patients Reaching Adulthood with CHD

2/3 have moderate and complex CHD

Adult CHD Patients

- 325,000 in 1970
- 500,000 in 1980
- 750,000 in 1990
- 1,000,000 in 2000
- 1,300,000 in 2010

20,000 new pts/yr
SOLUTION
Change The Outcome

WHO takes care of the patients

- Fall Between IM and Pediatric Cardiology Training

How Do We Change The Outcome For ACHD Patients
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.
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
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

Submitted in 2007

<table>
<thead>
<tr>
<th>Member</th>
<th>Representing</th>
</tr>
</thead>
<tbody>
<tr>
<td>Michael Landzberg, MD, FACC, Chair</td>
<td>ISACHD</td>
</tr>
<tr>
<td>Curt Daniels, MD, FACC, Co-Chair</td>
<td>ABP/ABIM</td>
</tr>
<tr>
<td>Elyse Foster, MD, FACC</td>
<td>AHA</td>
</tr>
<tr>
<td>Thomas Graham, MD, FACC</td>
<td>ABP</td>
</tr>
<tr>
<td>Gerard Martin, MD, FACC</td>
<td>ACC</td>
</tr>
<tr>
<td>Stephanie Mitchell</td>
<td>ACC</td>
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<tr>
<td>Amy Verstappen</td>
<td>ACHA</td>
</tr>
<tr>
<td>Carole Warnes, MD, FACC</td>
<td>ACC</td>
</tr>
<tr>
<td>Gary Webb, MD, FACC</td>
<td>ACC/ACHA</td>
</tr>
</tbody>
</table>
**Petition for ACHD subspecialty certification – American Board of Pediatrics**

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

**ABP Petition Writing Group**

<table>
<thead>
<tr>
<th>Member</th>
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<tbody>
<tr>
<td>Thomas Graham, MD, FACC</td>
<td>ACC</td>
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<tr>
<td>Curt Daniels, MD, FACC</td>
<td>ACC</td>
</tr>
<tr>
<td>Robert Beekman, MD, FACC</td>
<td>AAP/JCCHD</td>
</tr>
<tr>
<td>Michelle Gurvitz, MD, FACC</td>
<td>ACC</td>
</tr>
<tr>
<td>Gerard Martin, MD, FACC</td>
<td>ACC/JCCHD</td>
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<tr>
<td>Allison Knauth, MD, FACC</td>
<td>AHA</td>
</tr>
<tr>
<td>Catherine Webb, MD, FACC</td>
<td>JCCHD</td>
</tr>
<tr>
<td>David Sahn, MD, FACC</td>
<td>CHF</td>
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</tbody>
</table>
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 examinable and subspecialty certification available.
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
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 ≥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 inhospital 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.

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.

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%),
Change The Outcome

- ACHD Subspecialty Certification
- CHD Surgeons
- Multi-Center Research
- Evidence Based Clinical Guidelines
Alliance for Adult Research in Congenital Cardiology (AARCC)

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
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

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Change The Outcome

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

Diagnosed by cardiologist: 643 (100%)

Seen by cardiologist: 413 (64%)

Attrition: 177 (28%)

Only 40% still in CHD care

n=643 (100%)

n=643 (100%)

n=466 (72%)

n=343 (53%)

Attrition: 123 (19%)

Attrition: 51 (8%)

Attrition: 94 (15%)

n=643 (100%)

n=643 (100%)

n=466 (72%)

n=343 (53%)

Age Group

< 6

6-12

13-17

18-22

ACHD Patients in US vs Those in ACHD Clinics

Number Of Patients

1,000,000

800,000

700,000

600,000

500,000

400,000

300,000

200,000

100,000

0

1,000,000

LACK to Access

LOST of Care

38,000 in ACHD Clinics (4%)


ACHA Clinic Directory Working Group 2009
Change The Outcome

- 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

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.

- 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.
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

• 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 inter’al list, 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

**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

- 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
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
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
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 Toolkit

ACHD Webinars

Create Networking
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.
# Provider Action for Treating Congenital Hearts (PATCH)
## Program Webinars
### November 2012– May 2013

<table>
<thead>
<tr>
<th>Date</th>
<th>Time</th>
<th>Webinar Subject/Title</th>
<th>Presenter</th>
</tr>
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| November 27, 2012  | 7-8 pm EST | ACHD 101 for the Healthcare Provider  
| December 10, 2012  | 7-8 pm EST | ASD: What every non-CHD Provider Should Know  
| January 31, 2013   | 7-8 pm EST | CHD/PH Eisenmenger Syndrome  
| Date TBD           | 7-8 pm EST | Tetralogy of Fallot – The spectrum of late medical issues after repair  
| February 13, 2013  | 7-8 pm EST | Discussing Pregnancy and Birth Control with your CHD Patients  
| March 2013         | 7-8 pm EDT | Transposition (D-TGA, L-TGA)  
| April 2013         | 7-8 pm EDT | Single Ventricle/Fontan  
| May 2013           | 7-8 pm EDT | Bicuspid Aortic Valve/Coarctation  

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

Available presenter for local meetings:
John R. Lane, MD
Director of both Pediatric Cardiology and Adult Congenital Cardiology at Akron Children’s Hospital

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
Director, Adult Congenital Heart Disease Services

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
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
Ali Zaidi, MD - ali.zaidi@osumc.edu
Sharon Roble, MD, FACC - sharon.roble@osumc.edu

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
Gruschen Veldtman, FRCP, MBChB - gruschen.veldtman@cchmc.org
Gary Webb, MD, FACC - gary.webb@cchmc.org
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?

<table>
<thead>
<tr>
<th>Answer</th>
<th>0%</th>
<th>100%</th>
<th>Response Ratio</th>
</tr>
</thead>
<tbody>
<tr>
<td>During my cardiovascular fellowship training</td>
<td></td>
<td></td>
<td>23.0%</td>
</tr>
<tr>
<td>Articles and books when ACHD pts come through clinic</td>
<td></td>
<td></td>
<td>23.0%</td>
</tr>
<tr>
<td>I call an ACHD specialist for help</td>
<td></td>
<td></td>
<td>38.4%</td>
</tr>
<tr>
<td>I do not have a strategy and struggle to care for ACHD pts</td>
<td></td>
<td></td>
<td>15.3%</td>
</tr>
<tr>
<td>No Response(s)</td>
<td></td>
<td></td>
<td>0.0%</td>
</tr>
<tr>
<td>Totals</td>
<td></td>
<td>100%</td>
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### OHIO ACC SURVEY

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

<table>
<thead>
<tr>
<th>Answer</th>
<th>Response Ratio</th>
</tr>
</thead>
<tbody>
<tr>
<td>Listing of local and regional ACHD specialists and contact information</td>
<td>76.9 %</td>
</tr>
<tr>
<td>Easy access to ACHD educational material and case guidelines</td>
<td>92.3 %</td>
</tr>
<tr>
<td>ACHD webinars</td>
<td>15.3 %</td>
</tr>
<tr>
<td>Regional ACHD conferences</td>
<td>30.7 %</td>
</tr>
<tr>
<td>Other</td>
<td>0.0 %</td>
</tr>
<tr>
<td>Totals</td>
<td>100%</td>
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**Do you consult an ACHD specialist for patients with moderate and complex CHD**

<table>
<thead>
<tr>
<th>Answer</th>
<th>Response Ratio</th>
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<tbody>
<tr>
<td>Yes</td>
<td>100.0 %</td>
</tr>
<tr>
<td>No</td>
<td>0.0 %</td>
</tr>
<tr>
<td>No Response(s)</td>
<td>0.0 %</td>
</tr>
<tr>
<td>Totals</td>
<td>100%</td>
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</table>
“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?
Actuarial Probability of SCD-Free Survival After Surgical Treatment

![Graph showing actuarial probability of SCD-free survival over time for different procedures like d-TGA, TOF, COA, AS. The graph shows an improvement in survival and quality of life post-surgery.]
PATCH PANEL DISCUSSION

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PATCH Program Resources

PATCH Program website  www.patchheartprogram.org

American College of Cardiology  www.cardiosource.org

Adult Congenital Heart Association  www.achaheart.org

ACHA/ISACHD Clinic Directory
www.achaheart.org/home/clinic-directory.aspx
Adult Congenital Heart Disease

Improving Education and Communication Among Cardiologist

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