ACHD Clinics---the USA

Background
Congenital Heart Disease

A Continuum

Neonates
Infants
Children
Adolescents
Adults
This book includes all ages in order to give a complete, unified and uninterrupted impression of each malformation.

First Edition
Children Are Not Small Adults.
Adults Are Not Large Children.
Before World War II, congenital malformations of the heart were regarded as *hopeless futilities*, an occupation appropriate for the few women in medicine. Maude Abbott was advised by William Osler to occupy herself with the anatomic specimens at McGill, and Helen Taussig was advised to occupy herself with the *hopeless futilities* in the children’s clinic at Hopkins. Congenital heart disease in adults was unheard of.

But now, approximately 85% of infants with congenital heart disease in developed countries reach adulthood.

*The hopeless futilities have come of age.*
The Osler Library
McGill

1936
Maude Abbott’s 1936 Atlas

Still selling in 2012---$95.00 shipped FREE with Super Saver from Amazon.com.

An invaluable source of survival patterns before the advent of cardiac surgery.
The Blalock Taussig Operation 1944

Taussig’s Book 1947
BETHESDA CONFERENCES

22nd Bethesda Conference, October 1990
Congenital Heart Disease After Childhood:
An Expanding Patient Population
Joseph K. Perloff, Conference Chair

32nd Bethesda Conference, October 2000
Care of the Adult with Congenital Heart Disease
Gary Webb and Roberta G. Williams, Conference Chairs
Congenital Heart Disease
In Adults
The Future of Children
The Infant

The Postoperative Adult
The Future of Congenital Heart Disease

Despite remarkably precise anatomic and physiologic diagnoses and astonishing surgical feats, cures in the literal sense are few. We are therefore obliged look beyond the present and assume responsibility for the long-term care of new generations of patients with the sequelae and residua of postoperative congenital heart disease.
A Problem
Long Term Follow-Up
By Whom?

The relative geographic mobility of populations in the United States makes it unlikely that patients with congenital heart disease will remain under the long term care of their pediatric cardiologists.
**Adult Congenital Heart Disease in the U.S.**

Simple, moderately complex, complex: 900,000 to 1,000,000

About 20,000 open operations per year

Annual increase approximately 5% per year

Currently, there are more adults with CHD in the US than there are infants and children.
Resources in the United States

Specialty Board Certification

Pediatric Cardiology--------------------------1,200

Cardiovascular Medicine----------------------20,000
The Solution

Specialized Tertiary Care for Adults With CHD

Specialized facilities for the comprehensive care of adults with congenital heart disease offer services difficult if not impossible to duplicate by practicing physicians or in community hospitals.
London 1954
The National Heart Hospital

Los Angeles 2012
The UCLA Hospital
Adults with congenital heart disease are best managed in an adult setting, whether outpatient or inpatient. Clinic personnel must understand the surgical procedures, the post operative residua and sequelae, and the general medical illnesses that adults with congenital heart disease acquire during the course of aging.
Worldwide Organizations

International Society for

Adult Congenital Cardiac Disease
Patient Advocacy Group the United States

ACfHA
Adult Congenital Heart Association
Problems to be Resolved

Residua and Sequelae After Reparative Surgery for Congenital Heart Disease
A Problem Resolved
Pulmonary Hypertension

The pharmacologic treatment of pulmonary hypertension has been a major step forward.

Bosentan (Actelion)
Residua After Reparative Surgery

Valvular
Noncardiovascular
Electrophysiologic
Ventricular
Valvular Residua
Bicuspid Aortic Valve
Noncardiovascular Major Residua

Healed Brain Abscess
Noncardiovascular Minor Residua

Malformed Teeth in Williams Syndrome
Sequelae After Reparative Surgery for Congenital Heart Disease
Electrophysiologic Sequelae

**Left Bundle Branch Block**

<table>
<thead>
<tr>
<th>P Wave</th>
<th>PR Interval (in seconds)</th>
<th>QRS (in seconds)</th>
<th>Characteristics</th>
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<tbody>
<tr>
<td>Before each QRS, identical</td>
<td>.12 to .20</td>
<td>≥.12</td>
<td>RR’ in V5</td>
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Valvular Sequelae

Prosthetic Aortic Valve
Improvements will continue. What we have witnessed thus far may be the end of the beginning, but it is not the beginning of the end.