

ACHD Clinics---the USA

Background

Congenital Heart Disease

A Continuum

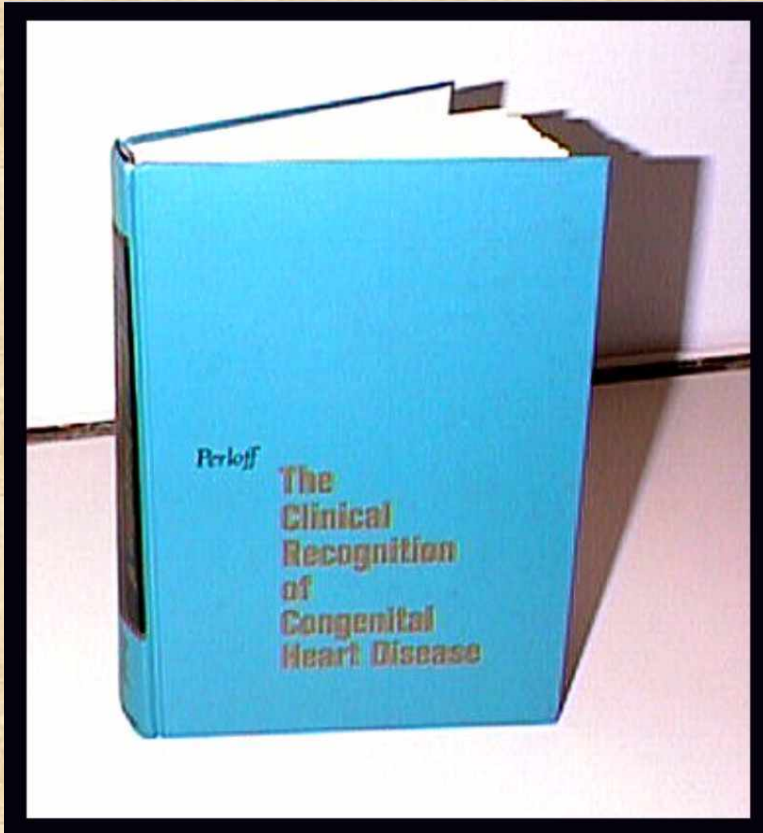
Neonates

Infants

Children

Adolescents

Adults



First Edition

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

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.



Maude Abbott



Helen Taussig

ATLAS
OF
CONGENITAL CARDIAC
DISEASE
MAUDE E. ABBOTT

1936

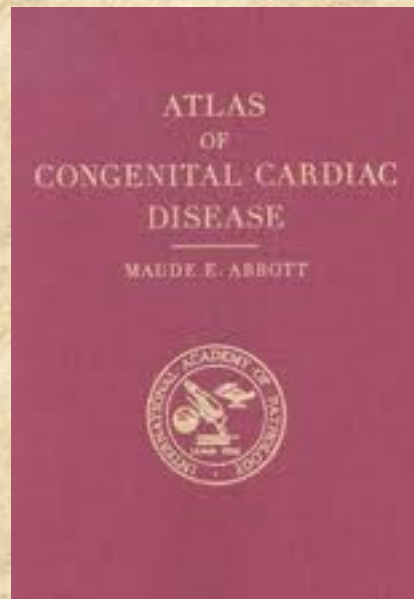
The Osler Library
McGill

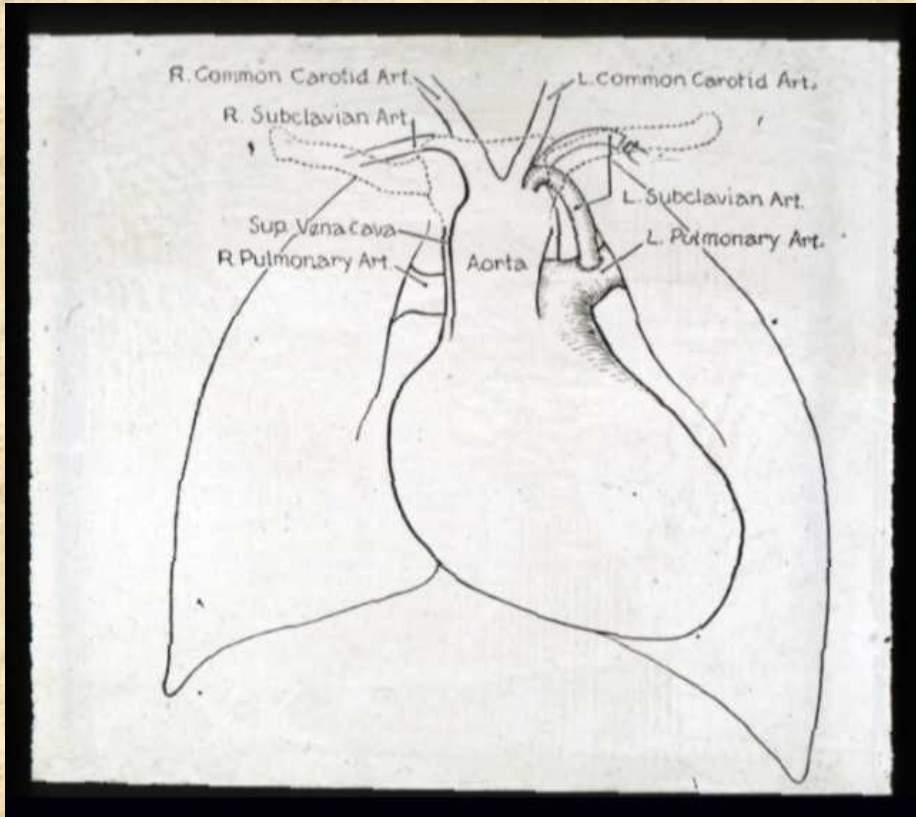


Maude Abbott's 1936 Atlas

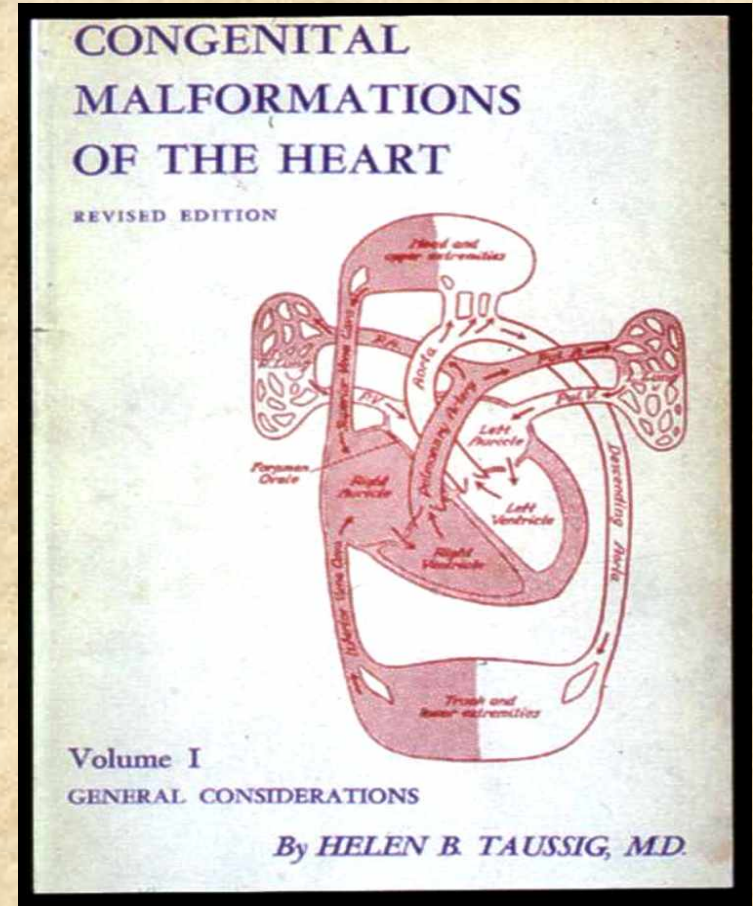
Still selling in 2012---\$95.00 shipped FREE with Super Saver from Amazon.com.

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

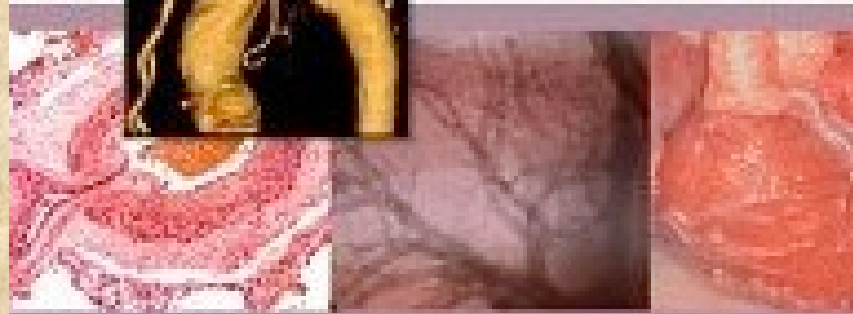
Gary Webb and Roberta G. Williams, Conference Chairs

Congenital Heart Disease In Adults The Future of Children

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Congenital Heart Disease in Adults

3rd Edition



Joseph K. Perloff

John S. Child

Jamil A. Aboulhosn

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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

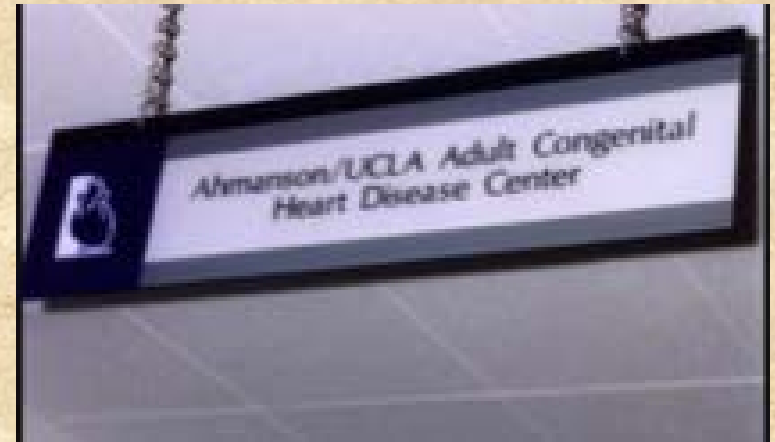
The Solution

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



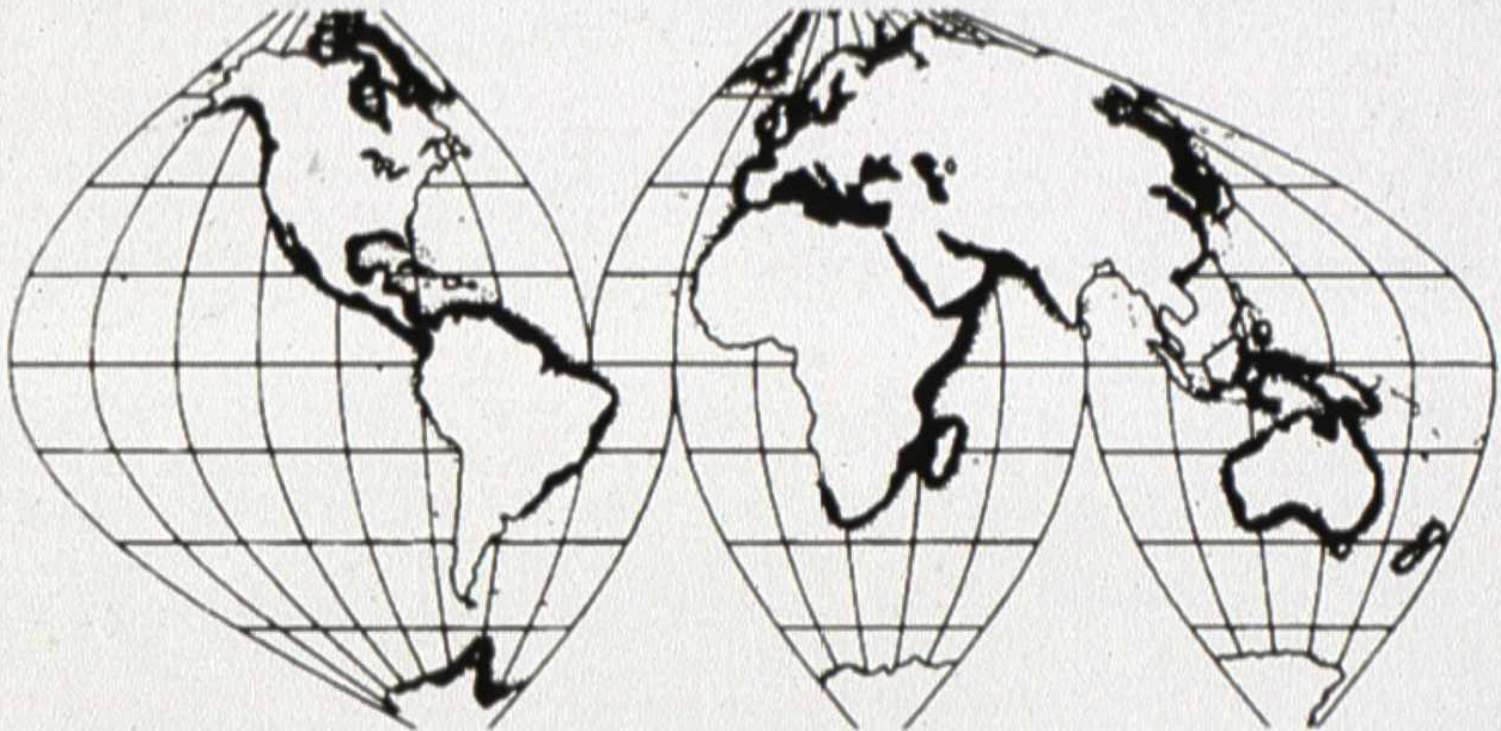
Los Angeles 2012
The UCLA Hospital

ACHD Clinics

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*



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

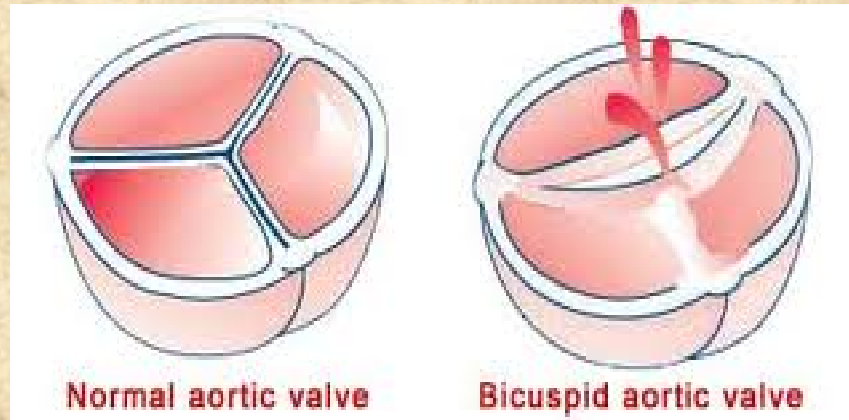
Noncardiovascular

Electrophysiologic

Ventricular

Valvular Residua

Bicuspid Aortic Valve



Noncardiovascular Major Residua



Healed Brain Abscess

Noncardiovascular Minor Residua



Malformed Teeth in Williams
Syndrome

Sequelaes After Reparative Surgery for Congenital Heart Disease

Electrophysiologic

Valvular

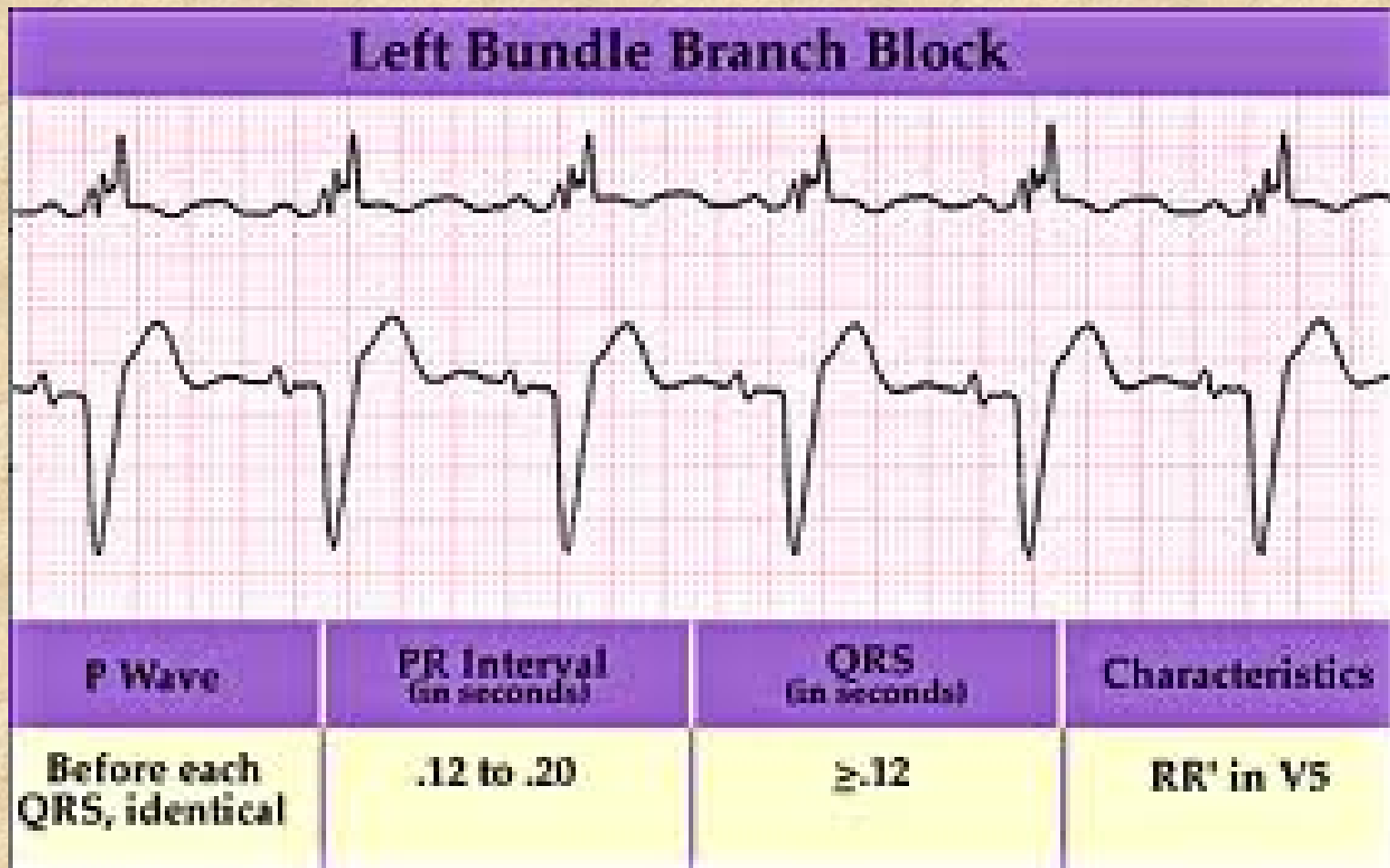
Prosthetic materials

Myocardial & Endocardial

Vascular

Neurologic

Electrophysiologic Sequelae



Valvular Sequelae



Prosthetic Aortic Valve

Good News



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.