ADULT CONGENITAL HEART DISEASE
Disclosures

• None
What Is Congenital Heart Disease (CHD)?

• Born with one or more heart structure abnormalities

• Defects range from simple, which might cause no problems, to complex, which can cause life-threatening complications
Who Do You Know?
Congenital Heart Disease Statistics

- 8-10 in 1,000 infants are born with CHD
- 4 in 1,000 infants have disease severe enough to need an intervention

Circulation, 2007;115
In 1940, the chance of surviving to the age of 18 with complex CHD was only 5%.

In 1970, this increased to 50%.

Currently, survival is now greater than 98%.
Patients Reaching Adulthood with CHD

- There are now >1.5 million adults in the US with CHD.
- Over 20,000 CHD patients turn 18 per year in the US.
- Now more than 2/3 of all CHD patients are adult.
ACHD in Florida

12,000 ACHD patients live in South Florida and SW Florida

How Did This Population Grow?
The first Cardiac Surgery

Cardiac Catheterization

Cardio - Pulmonary Bypass

Echocardiography

Adult Heart Transplant

Neonatal Open Heart Surgery

Research Surgical Modifications
Patients Often Are Lost to Follow Up as They Approach Teen Years

- 87% still follow with Primary Care
- Only 40% follow with Cardiology

ACHD Patients In The US Versus Those In ACHD Clinics

Lost to Care Lack of Access

38,000 in ACHD Clinics (4%)

ACHA Clinic Directory Working Group 2014
Lapse In Care For ACHD Patients Increases Their Morbidity

- 65% had a lapse in their care for 10 years or more
- These patients had an 8 times greater need for urgent intervention

Yueng, E et al. IJC. Sept 2006
As ACHD Patients Get Older Their Hospital Admissions Have Doubled
Modern Specialized Imaging Shows Unsuspected but Predictable Late Problems
Often Patients Get So Sick They Don’t Come In For Help

Taken from permission of patient
Deaths Decrease as Appropriate Referrals to ACHD Centers Increase
ACHD Recognized as a Subspeciality Board in 2016
ACHD Physicians Must Have Support of an Appropriate Center

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The Current ACHA Accredited ACHD Programs in the United States