



**It's Time to
Move On Kid:**

The Meaning of Transition in Congenital Heart Disease



Akron Children's Hospital

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Unfortunately...
I have no actual or potential conflict of interest
in relation to this program/presentation.



Objectives

- Identify the number of pediatric and adult patients living with congenital cardiac defects, and acquire an understanding of the need for specialized adult congenital heart disease (ACHD) care
- Differentiate between transition in congenital heart disease and transfer of care from pediatric to adult providers
- Recognize the positive impact the Pediatric Primary Care Provider has on continuity of care for the transitioning congenital heart disease patient





WHO??

1 million children

and

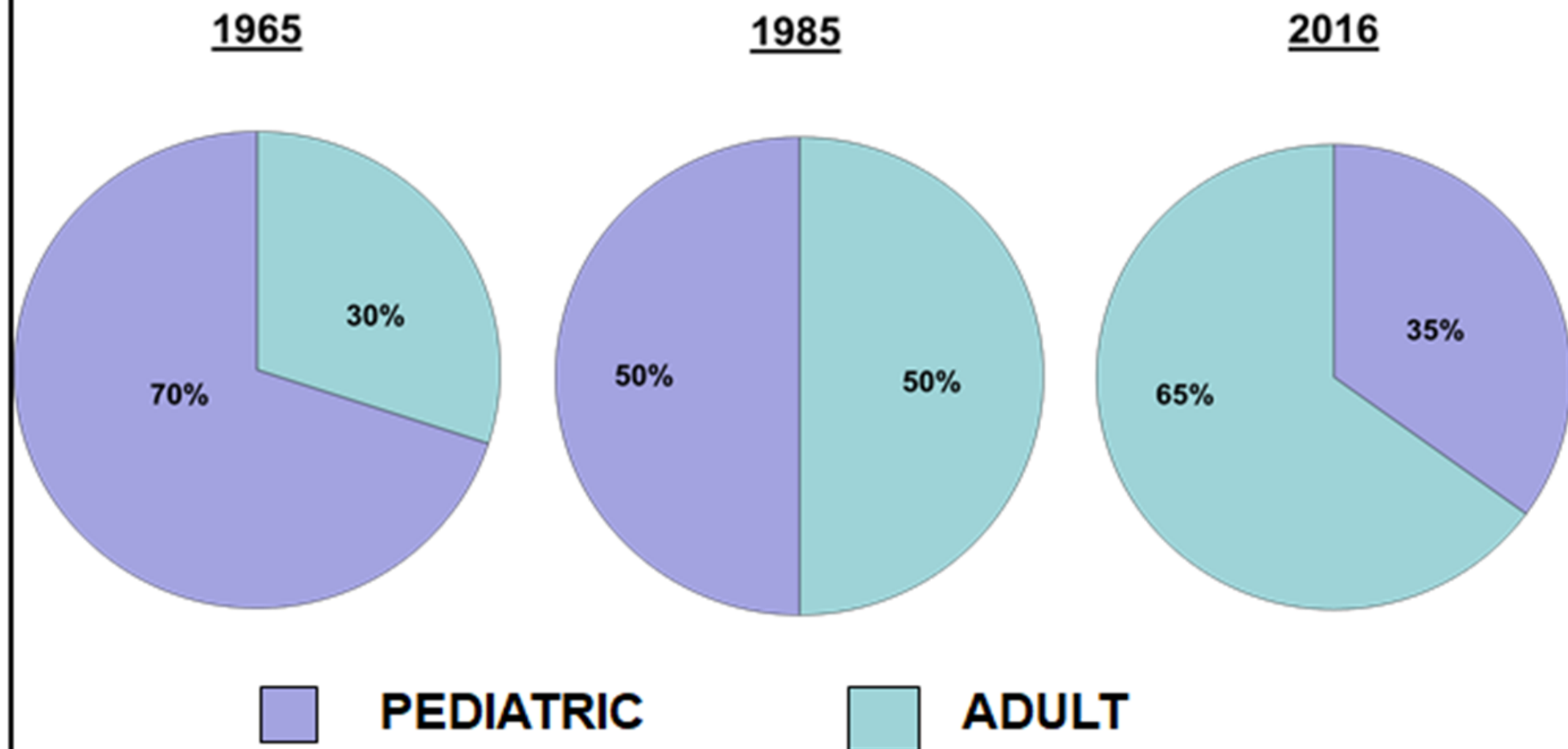
1.5+ million adults

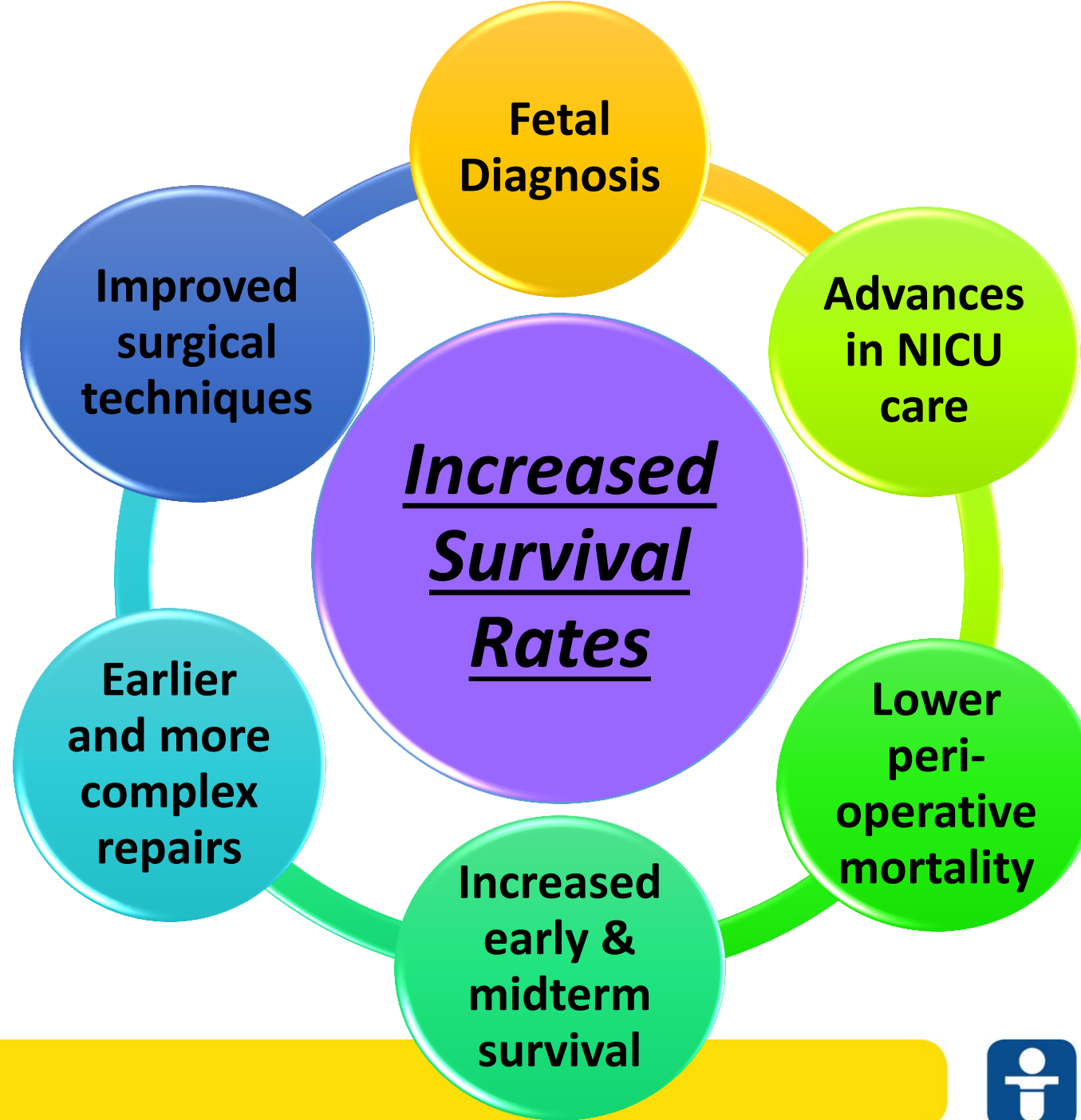
living with congenital heart disease
in the United States



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Changing Proportion of Pediatric and Adult CHD





WHO??



WHO??



Starting at 12 years of age



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WHAT??



Health Care Transition (HCT)

the purposeful, planned movement of adolescents and young adults with chronic physical and medical conditions from child-centered to adult-oriented health-care systems



Transfer of Care

the movement of patients and their care from one medical facility or provider to another.



Transition

is a planned educational process that occurs over **many** visits and years

Transfer

is a change from one provider to another;
it is often **unplanned and abrupt**



Health Care Transition? Or Transfer of Care?



Patient #1

- 20 y.o. female, hx “valve problem” since birth
- Seen 5 years ago by pediatric cardiologist
- Follow-up in 2 years was recommended
- Calling your office for referral to “adult heart doctor” at request of OB/GYN



Patient #1

- And she is pregnant
- Where should she go for her cardiac care??

Is this HCT or Transfer??



Patient #1

- Referral to Adult Congenital Heart Service at Akron Children's Heart Center
- Diagnosis is Bicuspid Aortic Valve with dilated aorta
- Followed closely during pregnancy along with MFM
- Delivered a few weeks early; open heart surgery within 6 weeks of delivery



Patient #2

- 14 y.o. female, single ventricle patient
- Pediatric Cardiology follow-up every 6 months
- Mother called before appointment with questions about support groups, prognosis, lifestyle choices and contraception questions



Patient #2

- Pediatric Cardiologist introduced ACHD coordinator and **Transition** was started
- Patient remains in care of her pediatric cardiologist
- Resources provided for educational needs and continued enforcement of need for lifelong congenital cardiac care

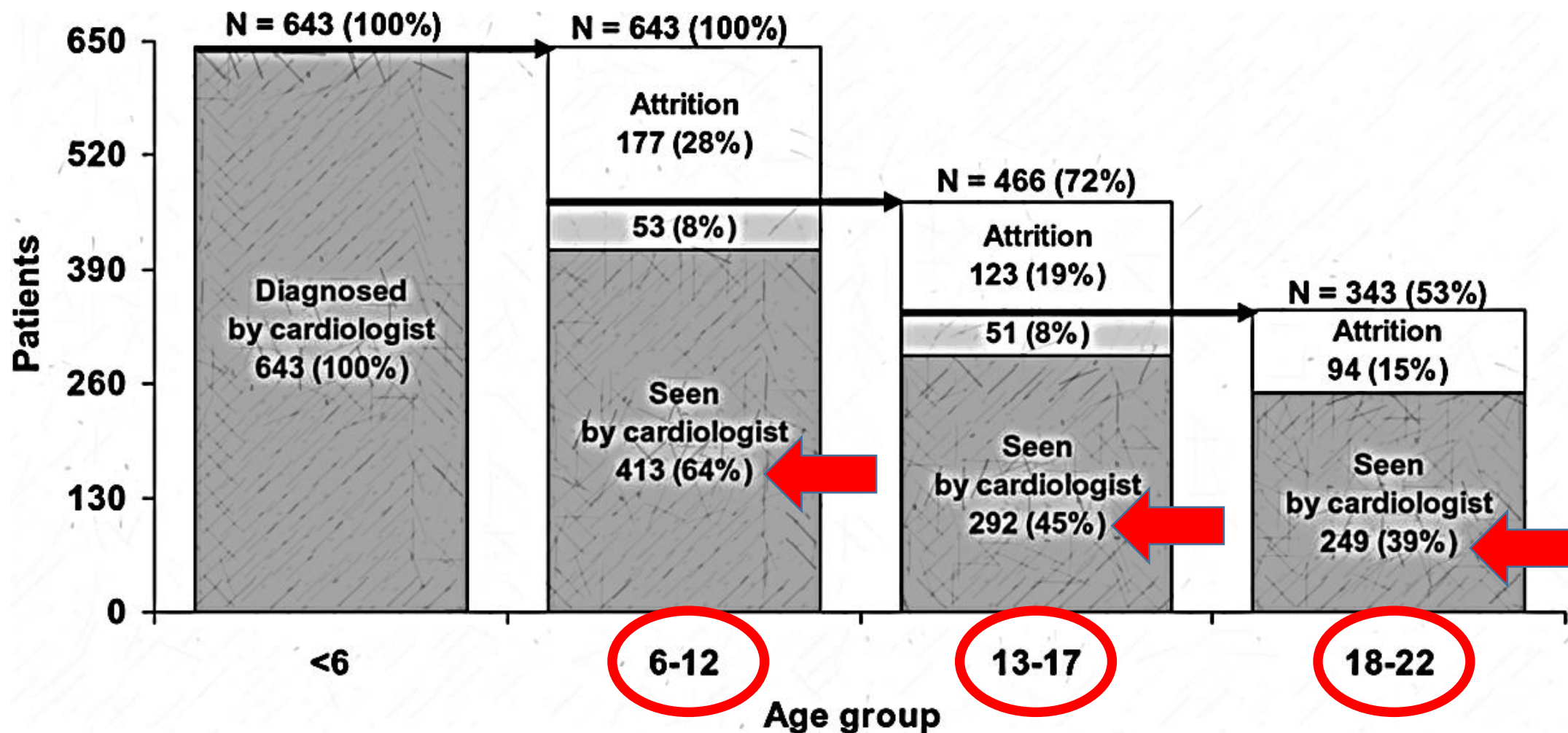


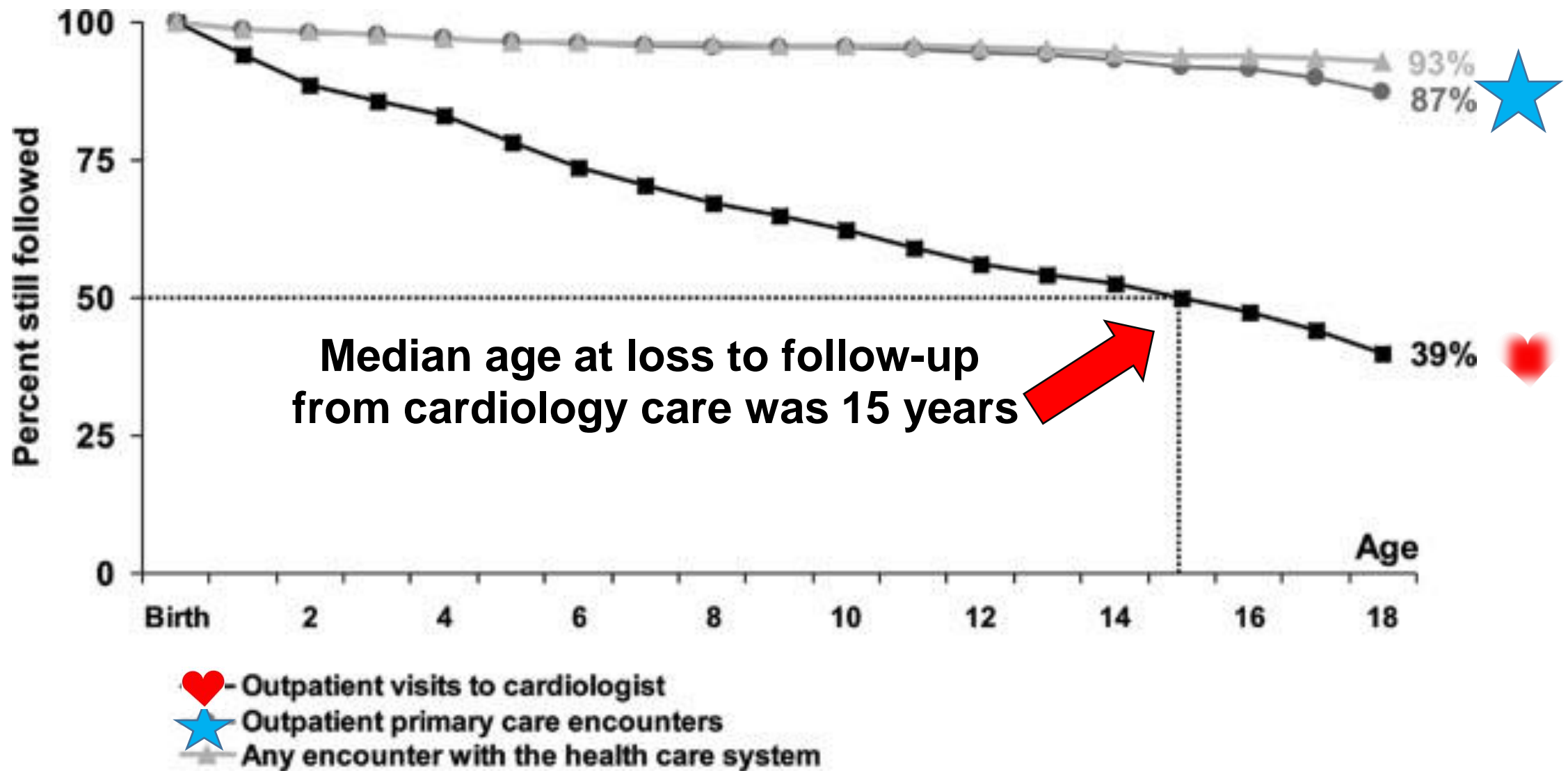
WHEN??

- Start the process early
- **Recommend by age 12 years**
- Include the parents/caregivers
- Envision a future at time of diagnosis and with each visit
- Start the process **EARLY!!**



Loss of follow-up from age 6 to 22 years





WHEN??

Start EARLY!!!



WHERE??



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WHY??

- It is the right thing to do
- Congenital heart disease is a chronic condition
- Congenital Heart Disease patients require ***lifelong specialized congenital cardiac care***



WHY??

- Patients with gaps in medical care have increased morbidity and mortality
- First major gap in medical care occurs in late teen years



WHY??

- Patients with lapse of medical care (≥ 2 years) are 3 times more likely to require urgent cardiac intervention
- 60% of patients had new diagnosis of hemodynamic significance on initial visit to adult congenital care after lapse or gap in care



HOW??

Transition

is a planned educational process that occurs over *many* visits and years



Transition Topics

- Name of congenital heart disease, native anatomy
- Interventions, procedures and surgeries
- Current anatomy and physiologic state
- Pacemaker, defibrillator, stents, coils in place



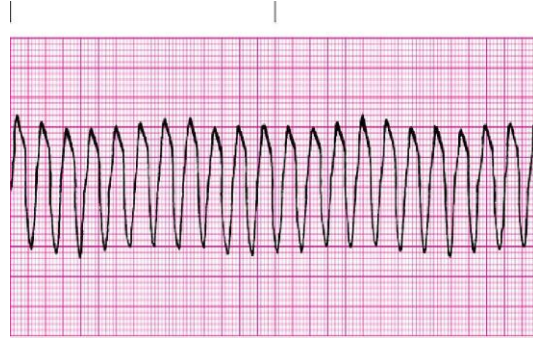
Transition Topics

- Residual hemodynamic considerations and issues to be anticipated based on individual's CHD
- Symptoms and how to respond; who to call and when

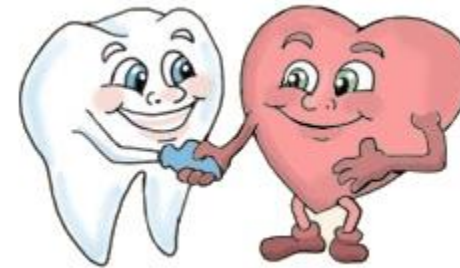


Transition Topics



- Arrhythmia considerations; risks, signs and symptoms



- Endocarditis considerations:
Risks, implications, recognition,
response, prevention



Transition Topics

- Non cardiac surgery considerations and risks; location of surgery, knowledge and skills of surgical team 
- Non cardiac medical problems; importance of Primary Care Provider 
- Access to appropriate care; is an ACHD center nearby?
(HINT* Akron Children's Heart Center*!)

Transition Topics

- Marriage and family planning
- Contraception and pregnancy planning
- Contraceptive options and risks
- Risks of pregnancy to mother and to fetus
- Management of pregnancy plan



Transition Topics

- Career, vocational, and insurance planning; health insurance, life insurance
- Lifestyle issues; tattoos, body piercings



Transition Topics

- High-risk behaviors and additional risks for CHD patients; alcohol and Fontan, tobacco, recreational drugs



Transition Topics

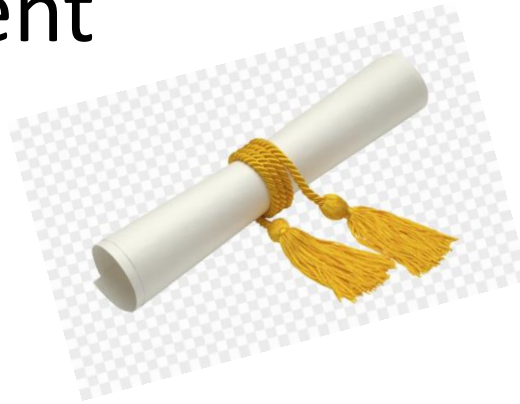
- Physical fitness recommendations; Exercise Prescription
- Activity restrictions



- Relative safety of exercise and hobbies; Skydiving? Roller Coasters? Rock climbing? Weight lifting?

Transition Topics

- Education, Employment



- Self-advocacy, Self-care



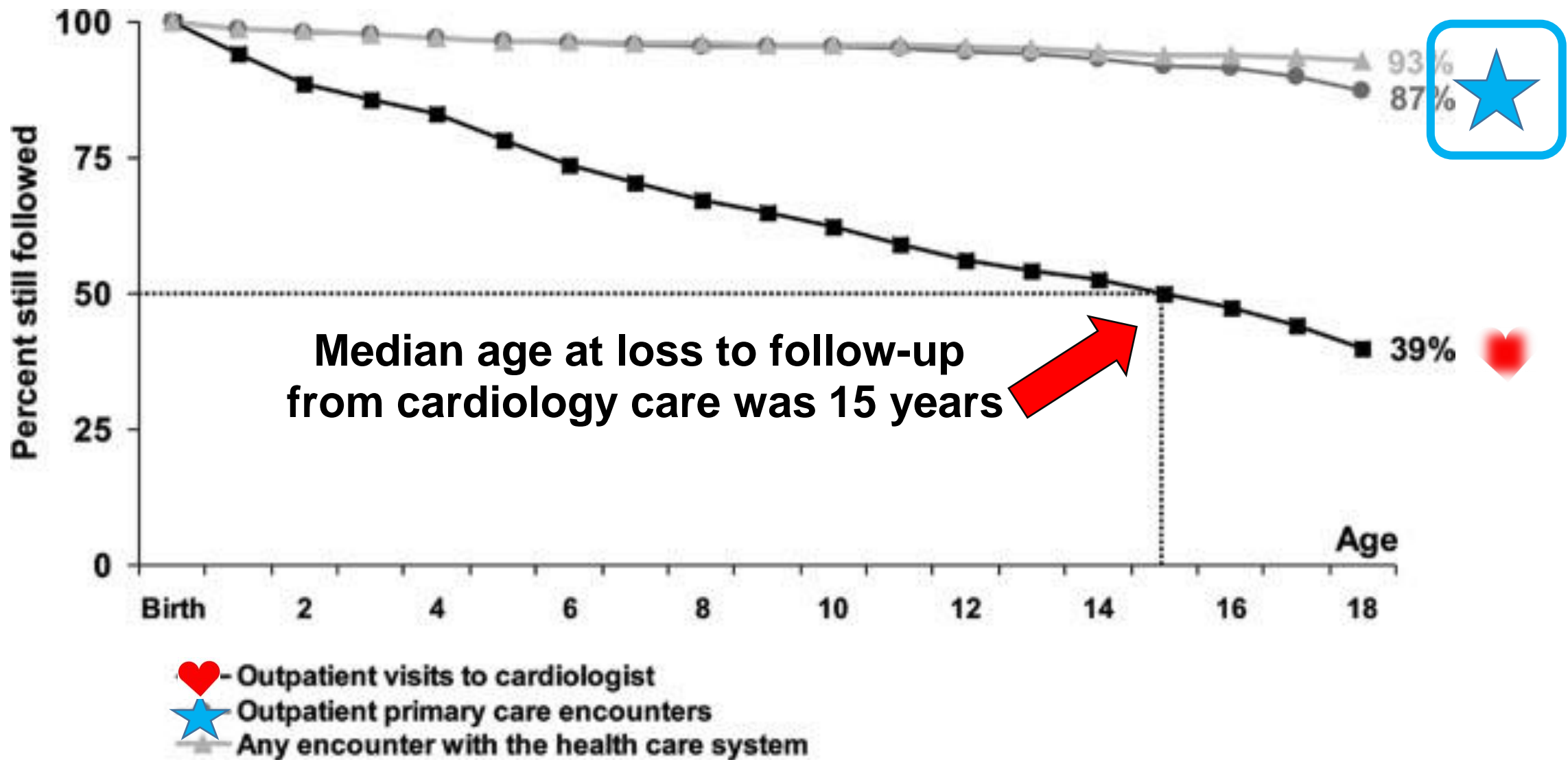
- Legal concerns; guardianship, Medical Power of Attorney, Advanced Directives

HOW??

Transition can only occur if we have
the patients to transition
This is where you come in...

How can YOU help?





Reasons for Return to Cardiac Care

Reason for Return to Care	Yes (%)
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Desire to prevent potential problems	70
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Recommendation from other health care provider 65

New symptoms or health problem(s)	53
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Recommendation from family/friends	47
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Desire to learn more about my heart	46
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Concern about potential deterioration	45
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New health insurance	26
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Emergency department visit	23
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Other life changes (e.g., marriage, new job)	23
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Better financial situation	19
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Interest in getting pregnant	14
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New adult CHD care services available	7
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Recommendation from health advocacy group	6
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Media story on CHD	3
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HOW??

- Remind your patients at each encounter to continue care with pediatric cardiology
- Primary Care Provider one of main reasons patients return to care
- Lapse of care increases morbidity and mortality



Adult Congenital Heart Service Team



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About Akron Children's

- Ranked a Best Children's Hospital by *U.S. News & World Report*
- Magnet® Recognition for Nursing Excellence
- Largest independent pediatric provider in northern Ohio
 - 2 hospital campuses
 - 60+ locations offering primary care, specialty services and urgent care
 - 5,800 employees
- With more than 1 million patient visits each year, we've been leading the way to healthier futures for children and communities through expert medical care, prevention and wellness programs since 1890.



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