



## Successful Transition of the Late Adolescent PH Patient: US vs. Canada/Europe Transition Programs

1<sup>st</sup> European Conference on Neonatal and Pediatric Pulmonary Vascular Disease  
October 3-4, 2013  
University Medical Center Groningen, The Netherlands




**Children's Hospital Colorado**  
A Children's Hospital of Aurora Children's Hospital Group

Beth A. Coleman RN, CPNP-PC  
Children's Hospital Colorado Heart Institute  
Pulmonary Hypertension Program



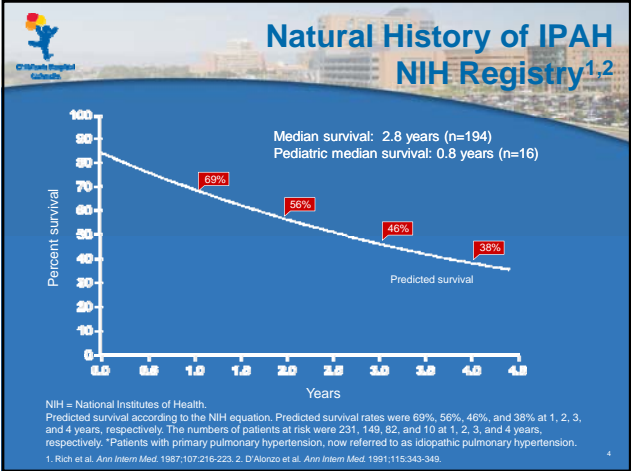
## Disclosures

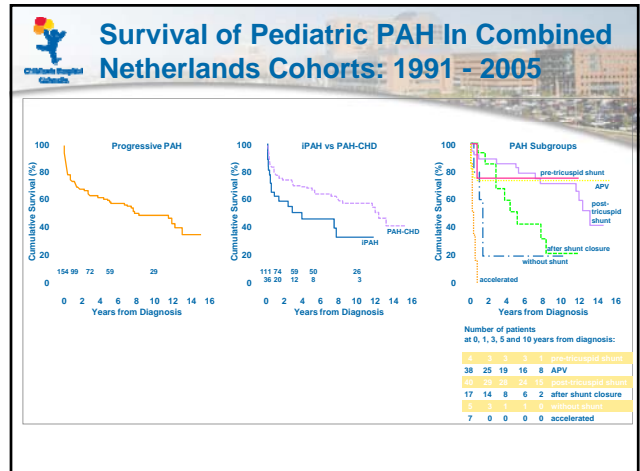
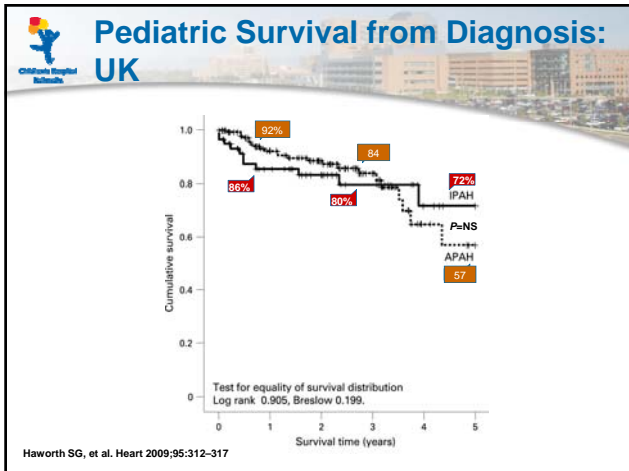
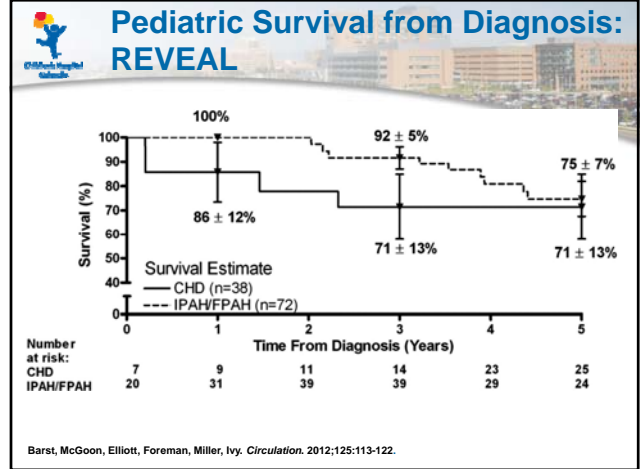
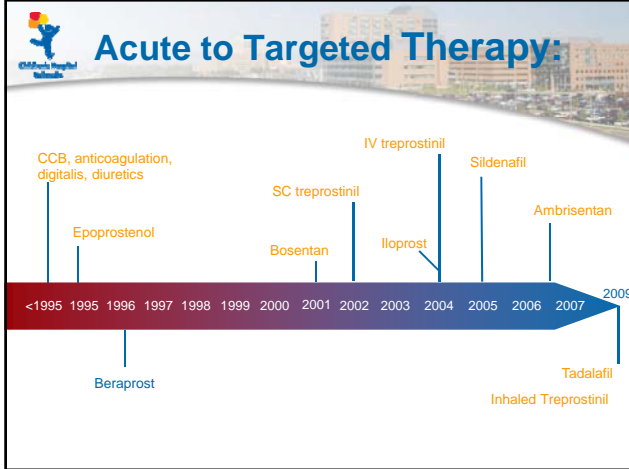
- United Therapeutics Advisory Board
- Actelion Advisory Board




## Objectives

- Substantiate need for formal transition program.
- Describe obstacles to transition program within the United States healthcare system.
- Propose transition program model








## A Fortunate Dilemma: Bridging the Gap

- Pediatric Model
  - Family Centered
  - Dependent on Parent
  - Family Oversight
  - CHD Associated PH
- Adult Model
  - Patient-Centered
  - Independence
  - Individual Accountability
  - Autonomy




## Different Healthcare Systems Different Challenges

- Government Supported Medicine
  - Center of excellence for country or region
  - PH patients transition to fewer Adult Program
  - Patients may live closer to PH Center
- Private Supported Medicine
  - Few Pediatric Centers
  - Many Adult Centers
  - Large geography of US
  - Many patients live out-of-state many miles from Pediatric PH Center



## Collaborative Transition = Successful Transfer

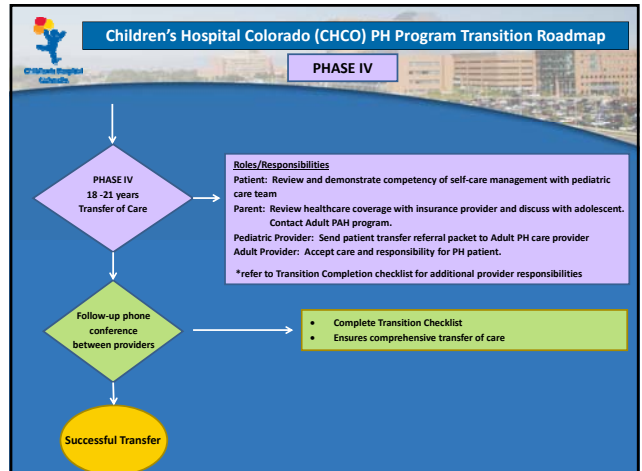
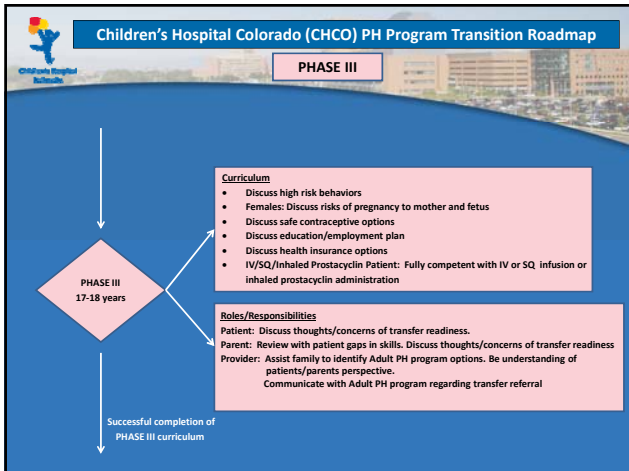
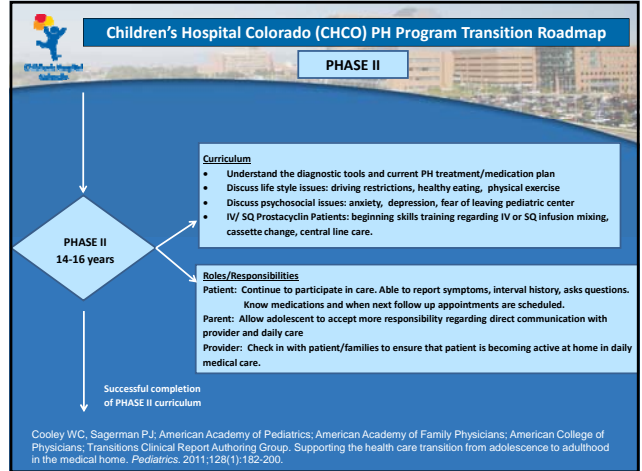
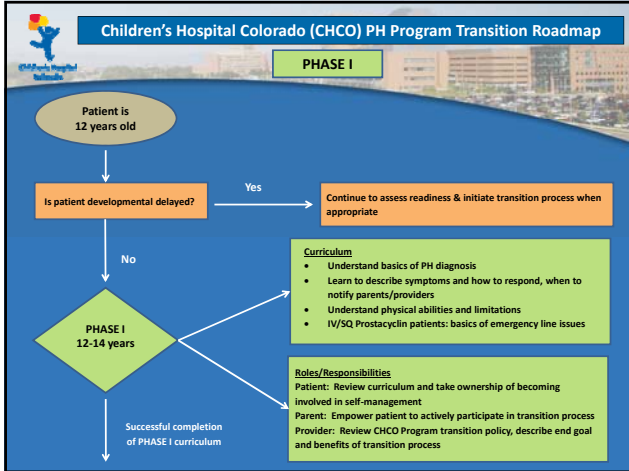
- Transition Program Barriers
  - Insufficient staffing
  - No identified staff members responsible for transitions
  - Financial challenges
  - Institutional acceptance
  - Resistance from adolescent and parents
  - Hesitancy of pediatric provider.
- Key Transition Concepts:
  - Timing
  - Patient, Family, and Provider readiness
  - Identification of adult PH care team
  - Buy-in from pediatric and adult programs
  - Successful completion of transition curriculum
  - Transfer of care



## Transition Models

- Society of Adolescent Medicine 1993 Position Paper
- Adult Congenital Heart Disease 2011 Best Practices Statement
- Cystic Fibrosis Foundation

• Sable C, Foster E, Uzark K, et al; American Heart Association Congenital Heart Defects Committee of the Council on Cardiovascular Disease in the Young, Council on Cardiovascular Nursing, Council on Clinical Cardiology, and Council on Peripheral Vascular Disease. Best practices in managing transition to adulthood for adolescents with congenital heart disease: the transition process and medical and psychosocial issues: a scientific statement from the American Heart Association. *Circulation*. 2011;123(13):1454-1485.  
 • Blum RW, Garell D, Hodgman CH, et al. Transition from child-centered to adult health-care systems for adolescents with chronic conditions. A position paper of the Society of Adolescent Medicine. *J Adolesc Health*. 1993;14(7):570-576.  
 • Chaudhry SR, Klinton M, Nasr SZ. Evaluation of a cystic fibrosis transition program from pediatric to adult care. *Pediatr Pulmonol*. 2012 Aug 8.






## Transfer Checklist

**Transfer Checklist**

- Patient/ family and pediatric PH provider determine readiness to transition
- Patient has successfully completed Phases I through VI of transition curriculum
- Adult PH provider identified and notified of transfer referral
- Adult PH Provider has accepted referral and has received transfer referral packet
- Patient has scheduled and completed first Adult PH Clinic visit
- Patient and parents have the Adult PH Program's contact information including contact process for emergency issues
- Telephone care conference between pediatric and adult providers to discuss issues. Confirm transfer of care complete and hand off successful.
- Patient has contacted all pharmacies, home health, and equipment providers with new PH provider information for future prescription management and care orders.



## Conclusion

- Dialogue
  - Adult Programs
  - PH Community
  - Pediatric Colleagues
- Commitment to Collaboration from Adult Colleagues
- Evaluation and Feedback Loop
  - Young Adults after Transition
  - Adult Colleagues
- Advocacy and Support from Pulmonary Hypertension Association and Pediatric Support Groups.




**Pulmonary Hypertension Program  
Children's Hospital Colorado**