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Presented by

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and two adults with CHD, Paige and Wanda

- \* There are currently more adults with CHDs than children.
- \* Older adults with CHD are acquiring coronary artery disease.
- \* Training programs need to approach care from both ends--the CHD factor and the "regular" cardiology care that comes from aging.
- \* Inova's clinic was started around 1994 and was Dr. Akl's vision.
- \* "Cowboy patients"--these are typically young adults through mid-20s. They fall off the radar and then pop back in during their late 20s or early 30s. But adults with CHDs need REGULAR FOLLOW UP. Doctors need to see the patients when they are healthy to plot the norms and recognize when a change occurs. Only 1/3 of adults with CHD regularly follow up!!!
- \* We need to let our kids start talking for themselves during appointments (around early teens). Let them talk to the medical staff including the medications and the name of their defect.
- \* We need to give privacy to our teens with their doctors. The doctors need to know what is really going on. We need to be able to step away from the room and let them talk.
- \* Drugs, drinking, and smoking--Use CHD as an extra piece with discussions with your adolescent: "You have a particular reason that makes these things worse for you." Drinking and heart failure is a "big no-no".
- \* Contraception--Discuss exact methods with physician. Pill may not be good with some defects.
- \* Pregnancy--Most adults with CHDs have a normal reproductive life. Plan with adult CHD cardiologist and perinatologist, seek genetic counseling and fetal echo. There is a higher chance (up to 20%) that an adult with CHD will have a child with CHD but not necessarily the same defect.
- \* Choosing a college--Should your child be near a reputable hospital? Have kids stay on schedule at school (meds, sleep, diet).
- \* Exercise--30 and 40 year-olds with CHDs never exercised because "they weren't allowed" and now they are overweight. Teach our kids to exercise now (always seek the advice of your child's cardiologist for specific details) so they can maintain a normal weight.
- \* Insurance--Keep them insured while they are full-time students. Have them choose jobs with better benefits. It is possible to get life insurance when the employer brings in a new vendor and there are no medical requirements.
- \* Age to Transition to Adult Care--Stay with your pediatric cardiologist through college.
- \* Records--Have your teenager/young adult keep a copy of: Op. Reports, echos, cath reports, letters from last couple of years. Parents keep a copy and patients keep a copy. **TEACH YOUR TEEN THE NAME OF THEIR DIAGNOSIS!!!**
- \* Call (215) 849-1260 to get your ACHA passport. This is a great way to document your young adult's information so that they can carry details of their medical condition with them.

The floor opened up to the adults with CHDs. They shared their stories and some insight.

Paige is a 33 year old with 3 different educational degrees and 3 children. She also has TGA and PDA.

Wanda is in her 50s and never had children (unrelated to her CHD). She has TOF.

\* Body issues/scars--Kids can be cruel. These women called them their beauty marks and badges of courage.

\* Treat your CHD kids as normally as possible.