

# Advice and life-long considerations for parents of children with heart disease: A doctors perspective

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## A little bit about me

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- Morehouse College in Atlanta, GA
- Case Western Reserve School of Medicine
- Pediatric cardiology fellowship at The Medical University of South Carolina  
—4<sup>th</sup> year in echocardiography

# Objectives

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- Insight into who is taking care of your child with heart disease
- Review of common cardiac tests
- How to ace the outpatient visit
- Life after cardiac surgery/procedure
- Parental tips to ensure adequate cardiac follow-up

# How to become a pediatric cardiologist?

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- Training in general pediatrics 3 years
  - Most are board certified in general pediatrics
- Special interest in taking care of kids (and adults) with heart disease
  - 3 years of fellowship training
  - +/- 1 year of additional training

# Cardiac Subspecialties

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- Echocardiography
  - Foundation of diagnosing heart disease
  - Experts in ultrasound interpretation
  - Often perform fetal consultation
- Electrophysiology (or “EP”)
  - Heart rhythm abnormalities
  - Pacemaker and ICD
- Heart Failure/Transplant
- Adult Congenital
- Intensive Care
- Cardiac Catheterization

# How do I prepare for your visit?

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- Review medical records and surgical information
- Determine what follow-up testing needs to be performed
  - ECG
  - Echo
- Review what questions I need to ask depending on your child's condition
  - THE HISTORY (OR QUESTIONING) IS KEY DURING OUR VISITS AND MAY SEEM REPETITIVE

# Obtaining a history from an older child or teen

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<http://laughlines.blogs.nytimes.com/category/submit-your-funny-caption/page/6/>



[http://a.abcnews.com/images/Health/gty\\_teen\\_texting\\_mr\\_120701\\_wmain.jpg](http://a.abcnews.com/images/Health/gty_teen_texting_mr_120701_wmain.jpg)



# Important history questions

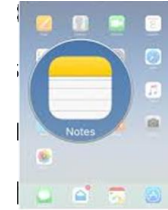
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- Babies/infants
  - How is the baby feeding?
  - Do they feed comfortably or look labored?
  - Energy level
  - Oxygen levels
  - Weight gain
- Teens
  - Energy level
  - Funny or fast heart beats
  - Breathing difficulty or shortness of breath
  - Swelling
  - Diarrhea (Fontan patients can lose protein in stool)

# How should YOU prepare for the visit?

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- Write down questions and concerns!!!!!!
- Create a medication list
  - Need any refills?
- Recall any surgeries, ER visits, or new medical issues
- Sports participation
- Change in insurance coming soon?
- Easily removable clothing
- Bring a distraction
  - Toys, books, Ipad, homework



# Waiting room life: What is taking so long?

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# What is happening behind the scenes

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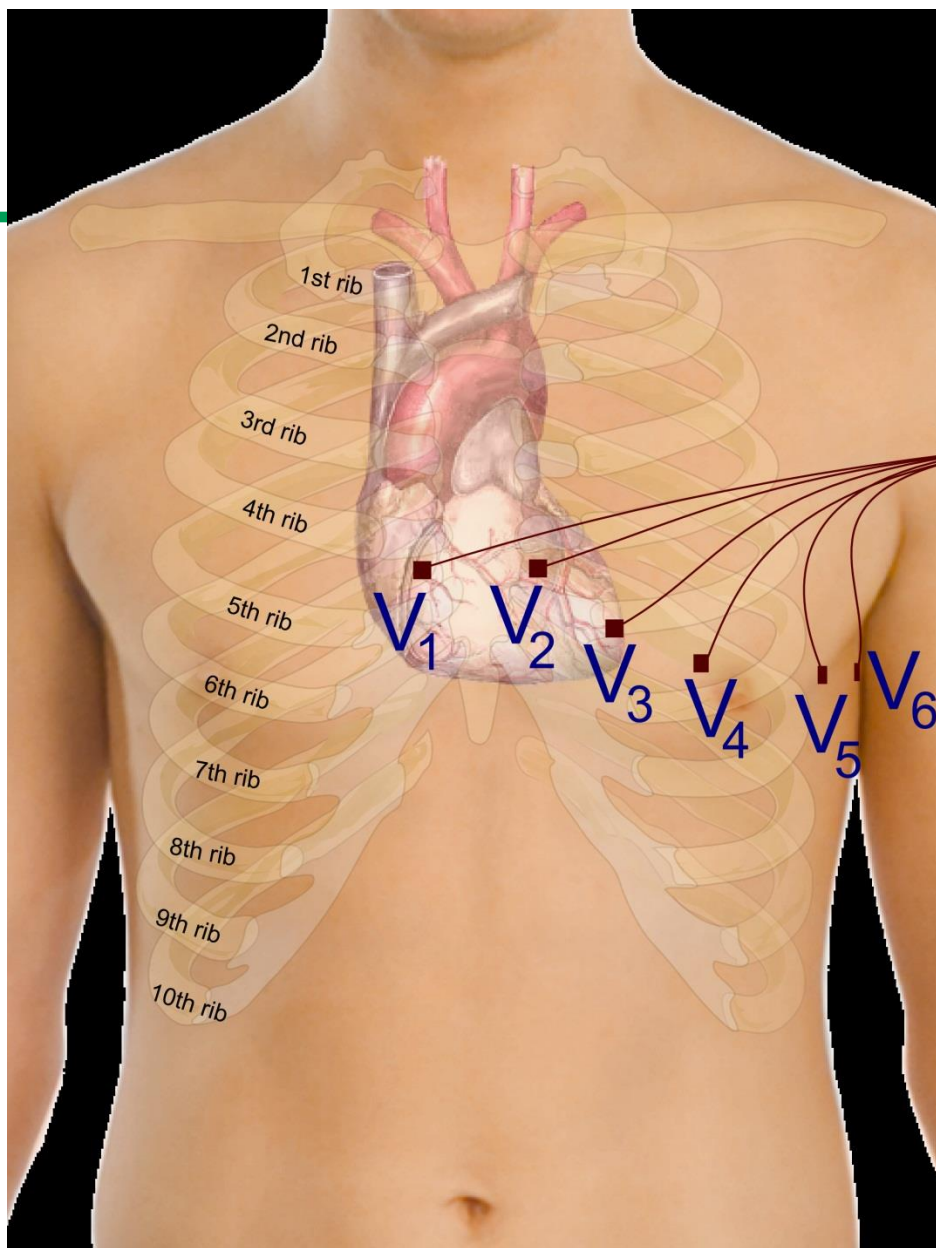
- Unlike most practices we review every single test and echo image before we send you home
- Emergencies occasionally happen which require coordination of transfer to Egleston
- Significant heart disease may be diagnosed in the office and result in long discussions that many of you have experienced
- Electronic charting to capture details of visit and sometimes technology acts up
- Every effort is made to balance a quick visit and adequate face-to-face time with the physician
- Understand there is variability between physicians

# Cardiac Testing

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- Vital signs
  - Heart rate
  - Blood pressure
    - Arm and leg
    - Leg should have higher blood pressure
  - Oxygen level (Saturation or “Sat”)
  - Weight
    - Important for babies

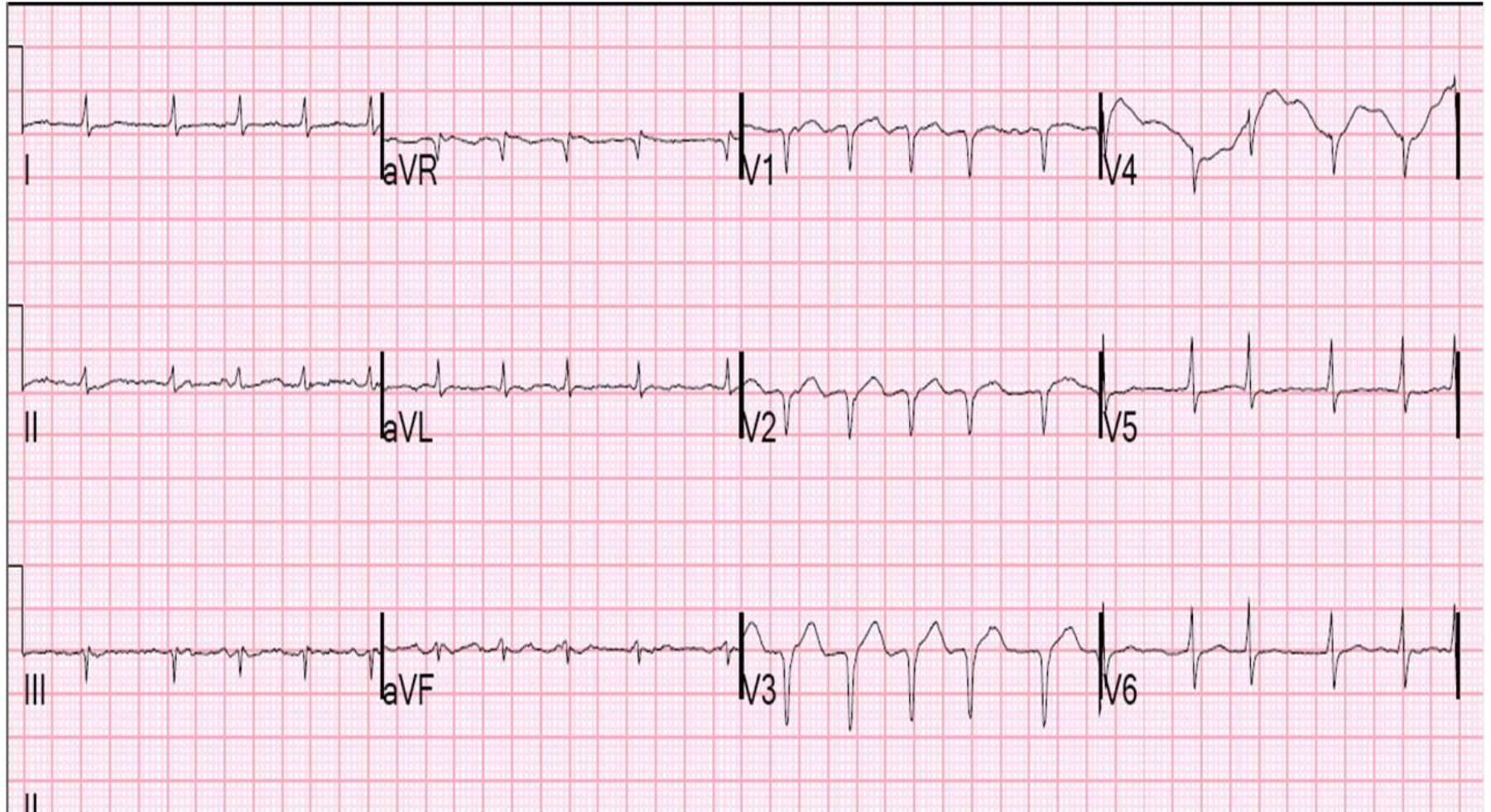
# ECG



[http://upload.wikimedia.org/wikipedia/commons/4/41/Precordial\\_leads\\_in\\_ECG.png](http://upload.wikimedia.org/wikipedia/commons/4/41/Precordial_leads_in_ECG.png)

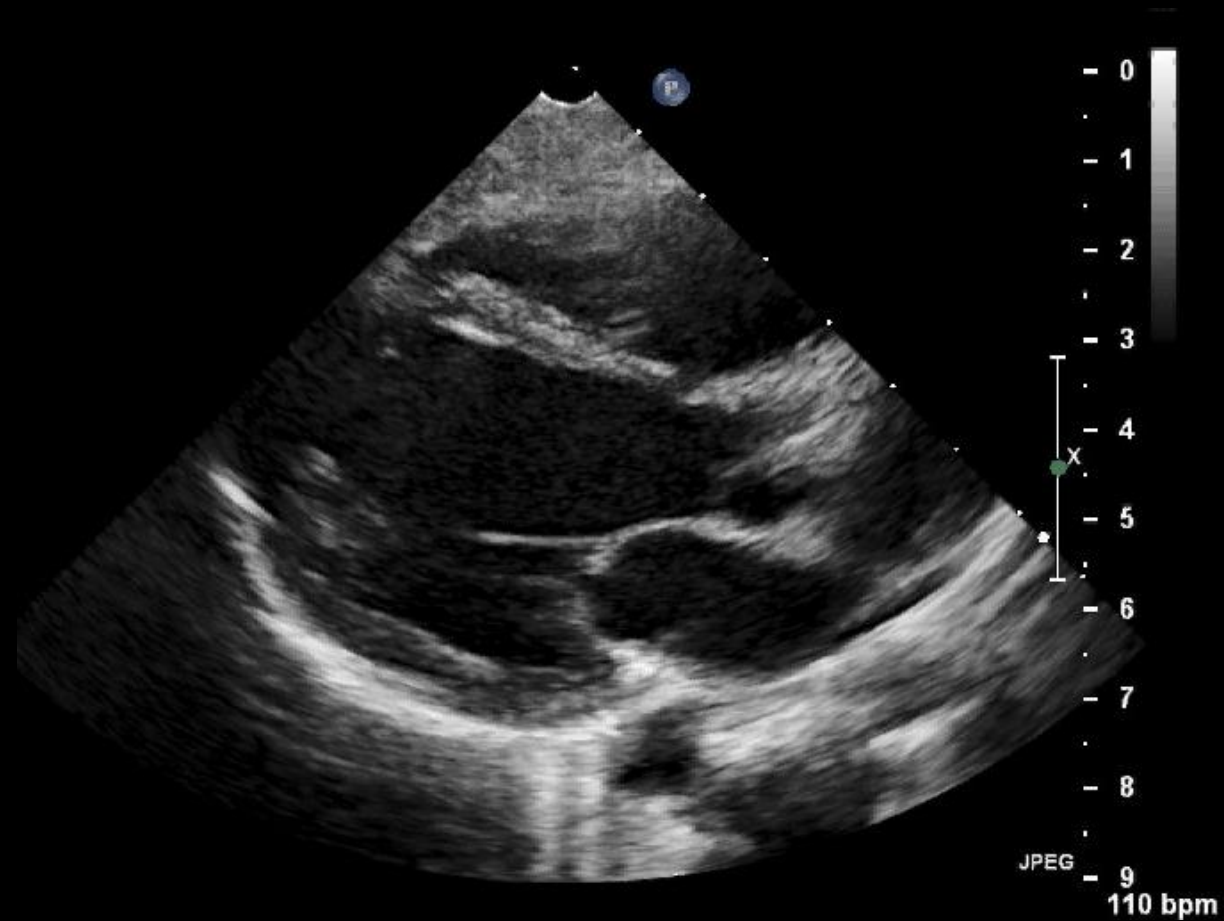
# Electrocardiogram (ECG or EKG)

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# Echocardiogram “Echo”

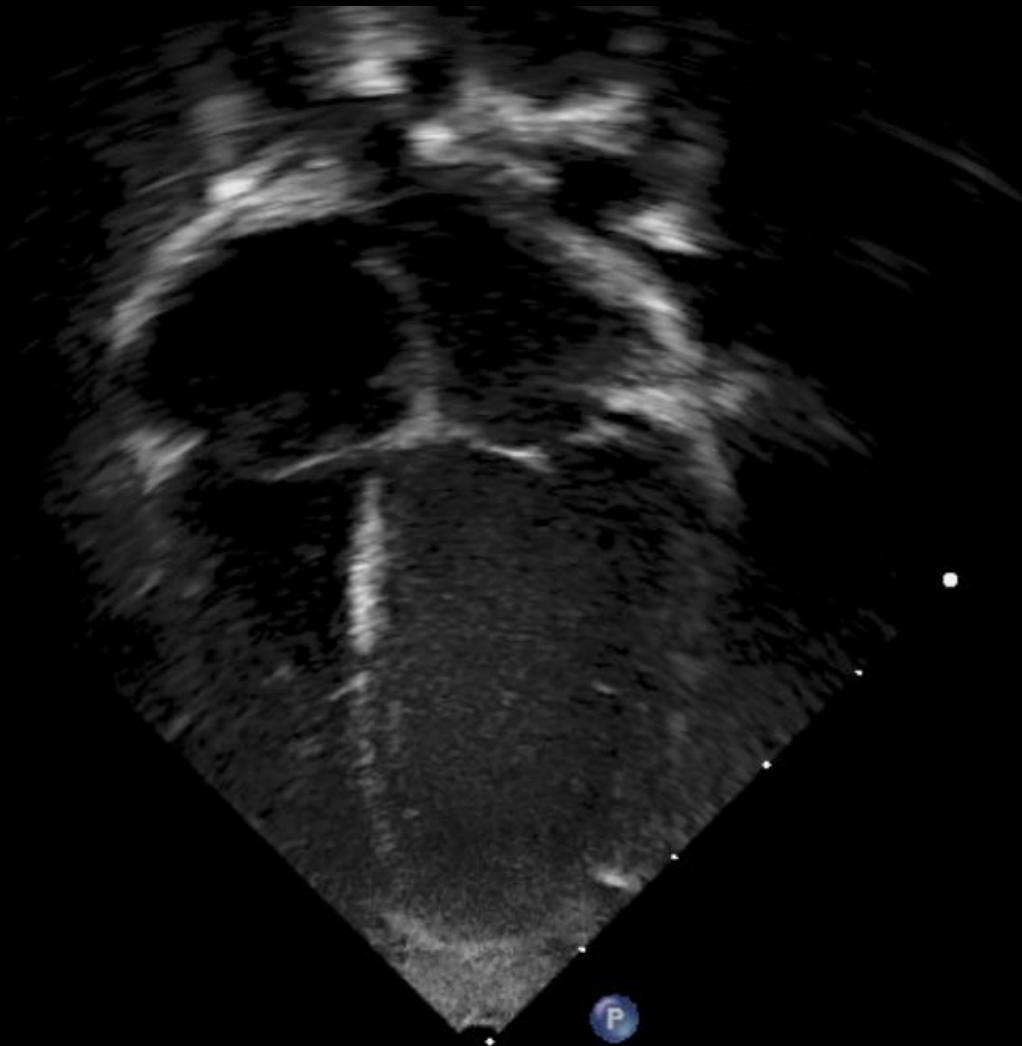
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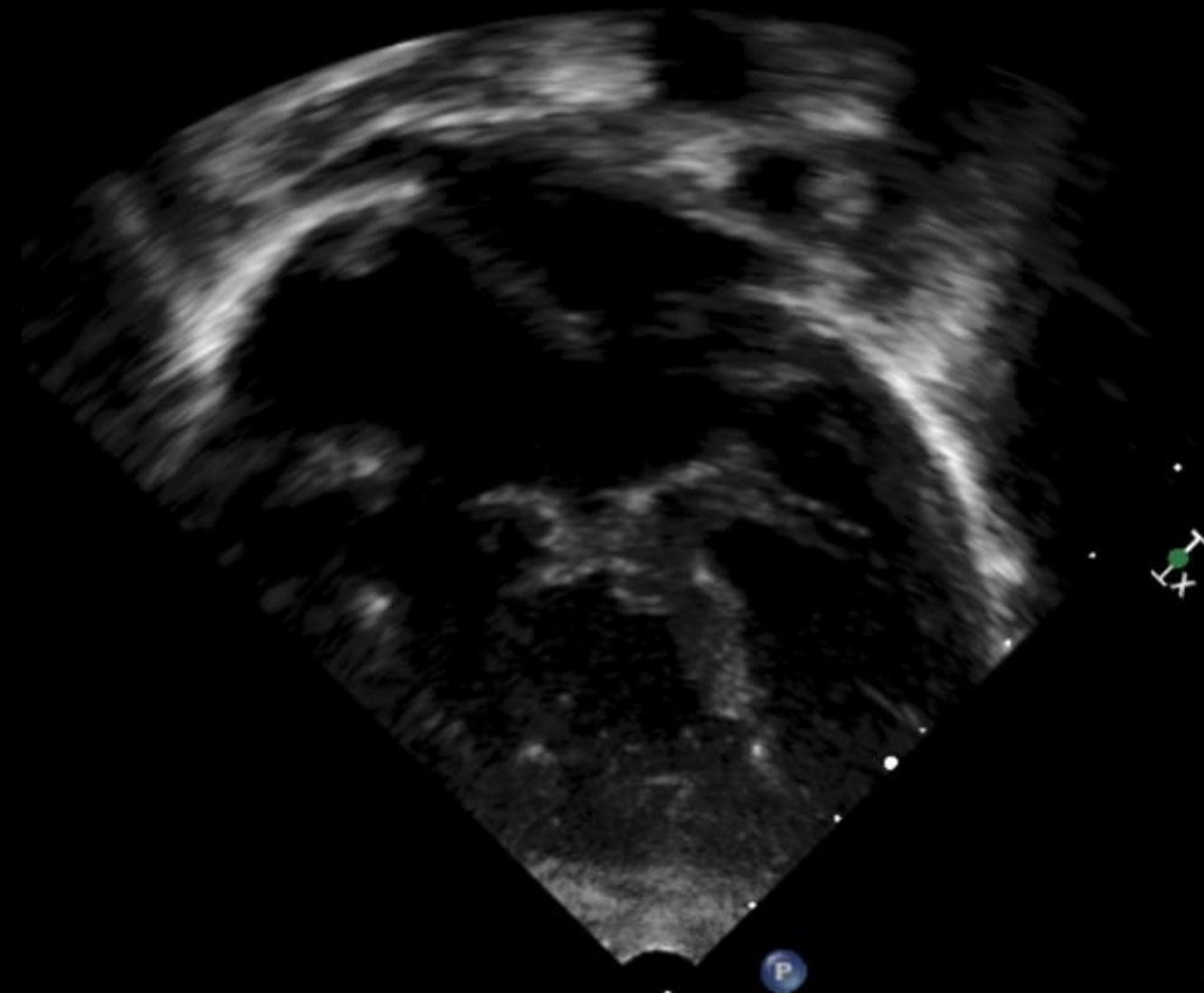
# Normal 4 chamber view

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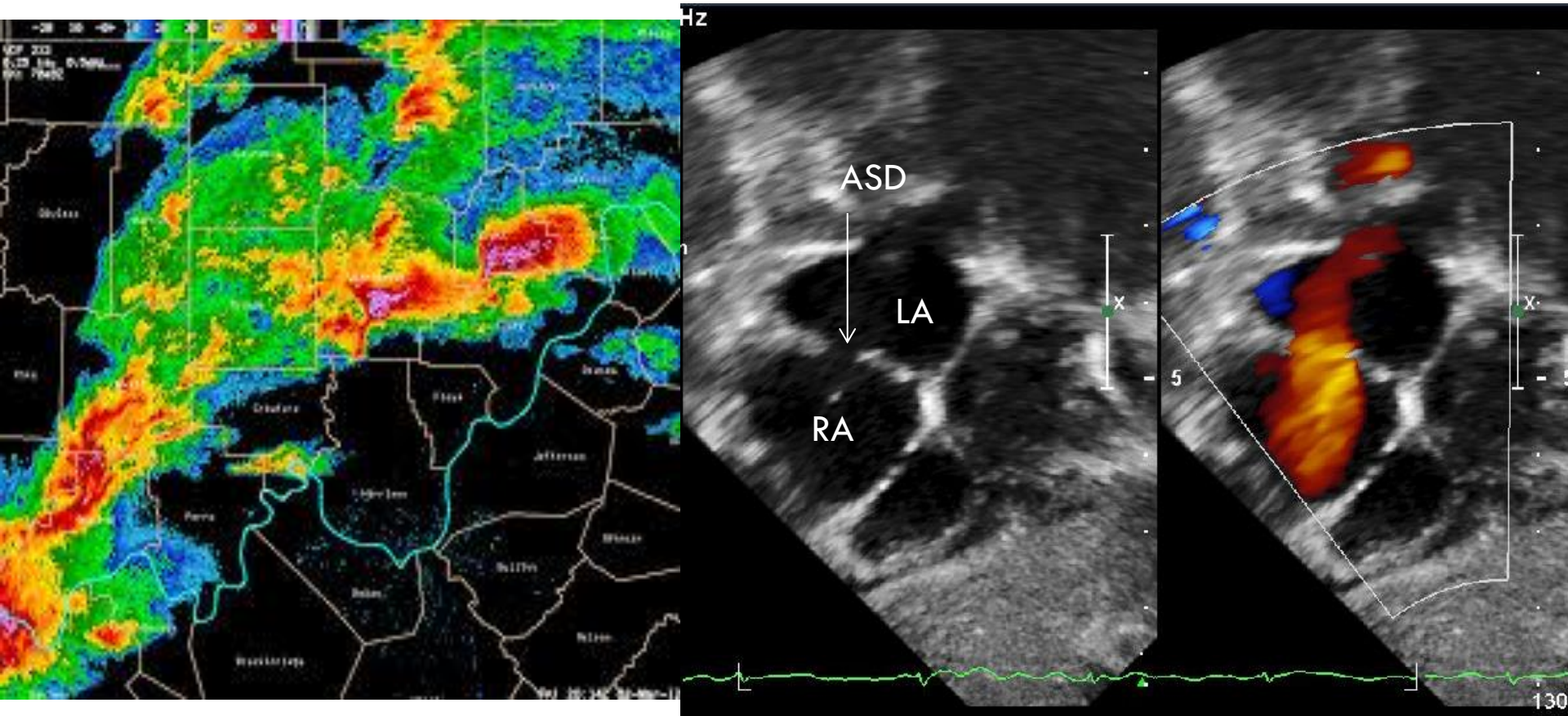
# AV Canal Defect

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# Color Doppler

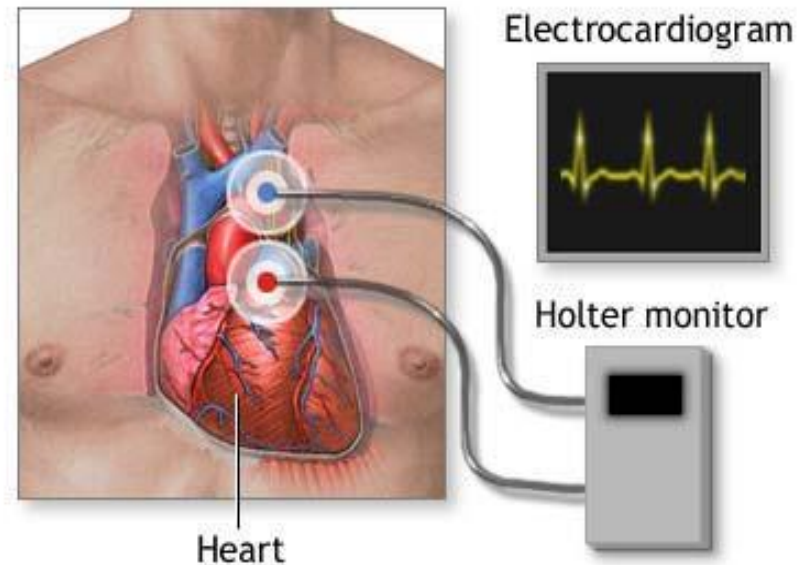
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# Monitors

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- Holter monitor
  - 24 hour ECG recording
  - Tetralogy of Fallot
  - Hypoplastic left heart syndrome
- Event monitor
  - Recording is triggered by the patient
  - “Heart fluttering”
  - Palpitations
  - Dizziness



# Exercise Stress Testing

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- Treadmill or Bicycle
- Evaluate heart rhythm and function
- Evaluate breathing and oxygen levels
- Blood pressure response
- Determine if exercise is safe for your child



# Cardiac MRI or CT

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# Differences between CT scan and MRI

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- CT scan
  - Only takes a couple of minutes for image acquisition
  - May require sedation but often we can use a “feed and bundle approach”
  - Radiation
    - Less radiation with new generation scanners and pediatric scans often do not require as much radiation as adults
- MRI scan
  - Can take 1-4 hours depending on the complexity of heart disease
  - Sedation more commonly needed due to length of scan and need for patient to hold still for a while and breath on command

# What is important to know as a parent?

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- Medical History
- Surgical history
- Medications
- Allergies
- Follow-up visits



# Use technology to keep things in order

## < Notes

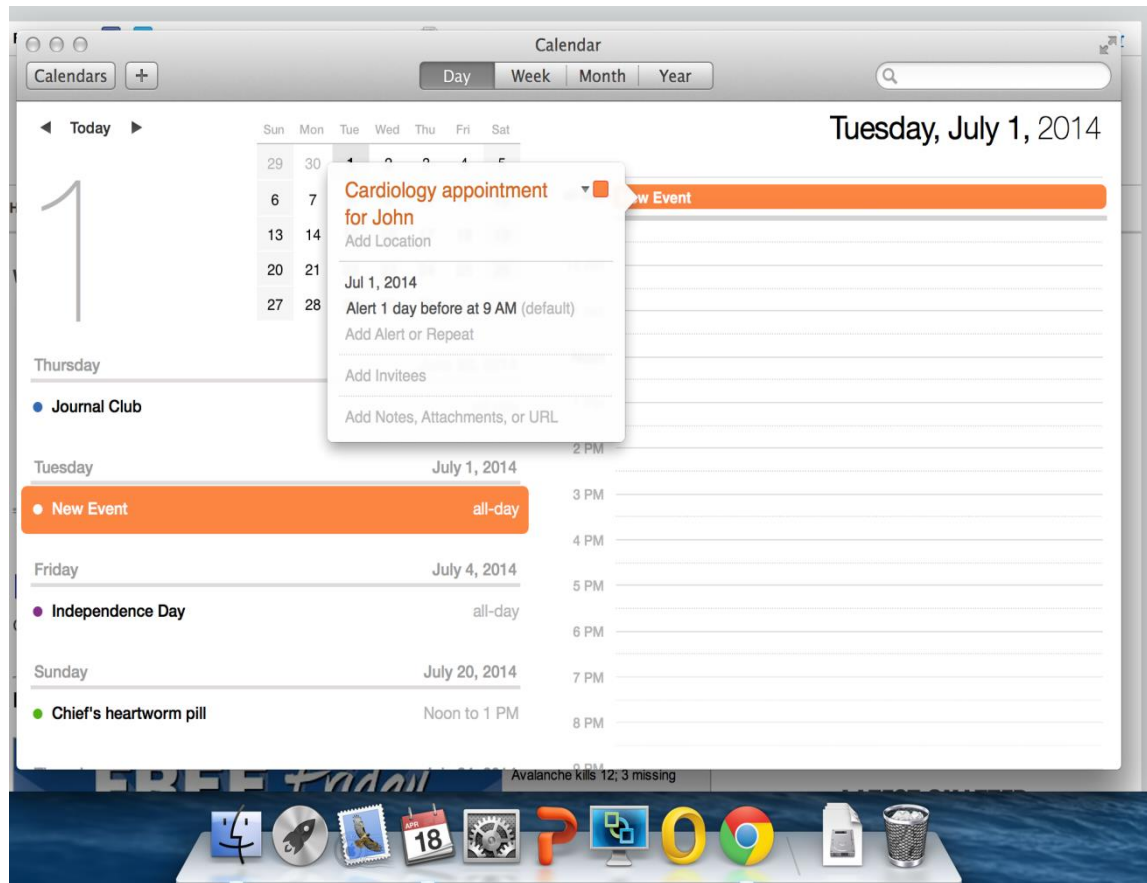
April 18, 2014, 8:53 AM

Coarctation of the aorta

Coarctation repair on 4/12/11  
at Emory in Atlanta

Needs right arm blood  
pressure!!!!

Allergies: Penicillin  
Cardiologist : Dr Watson  
[404-256-2583](tel:404-256-2583)



# The land of happiness – Right?

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# Amusement Park Cautions

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- Heat and dehydration
- Standing in long lines
  - Pooling of blood in legs
- A lot of walking/running
- Adrenaline stress with rides

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All Children's Hospital (Florida)  
Arnold Palmer Hospital for Children & Women  
Baptist Children's Hospital (Miami, Florida)  
Chris Evert Children's Hospital  
Florida Children's Hospital  
Joe DiMaggio Children's Hospital  
Miami Children's Hospital Pediatric Healthcare  
Shands Children's Hospital  
St. Joseph's Children's Hospital of Tampa  
Tampa General - Children's Medical Center  
Tampa Shriners Hospital  
The Children's Hospital of Southwest Florida  
Wolfson Children's Hospital

# Tips for vacation

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- Keep your child well hydrated!
- Take breaks if needed
- Do not cram in too much in one day
- Know where the local CHILDRENS' emergency room is located near your destination.
- Have a number to call
- Medication information
- Never check your medication bag

# Adolescent and adulthood

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- Make sure your teen knows his/her heart condition
- They will need to take ownership of their health
- Need for transition of care to a specialist with training in congenital heart disease
- Make note when follow-up visits are needed
  - Spring break, Christmas, Summer break
- Birth control !!!!!
  - This discussion must happen

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- [Drugs and therapeutics, including contraception, for women with heart disease.](#)
1. Mohan AR, Nelson-Piercy C.  
Best Pract Res Clin Obstet Gynaecol. 2014 Mar 21. pii: S1521-6934(14)00047-9. doi: 10.1016/j.bpobgyn.2014.03.005.  
[Epub ahead of print]  
PMID: 24721288 [PubMed - as supplied by publisher]  
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  2. [Addressing Sexual Health in Congenital Heart Disease: When Being the Same Isn't the Same.](#)  
Loomba RS, Aggarwal S, Pelech AN.  
Congenit Heart Dis. 2014 Feb 13. doi: 10.1111/chd.12168. [Epub ahead of print]  
PMID: 24521242 [PubMed - as supplied by publisher]  
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  3. [Key issues of daily life in adults with congenital heart disease.](#)  
Ladouceur M, Iserin L, Cohen S, Legendre A, Boudjemline Y, Bonnet D.  
Arch Cardiovasc Dis. 2013 Jun-Jul;106(6-7):404-12. doi: 10.1016/j.acvd.2013.02.004. Epub 2013 Jun 24.  
PMID: 23806303 [PubMed - indexed for MEDLINE]  
[Related citations](#)
  4. [Usefulness of progesterone-only components for contraception in patients with congenital heart disease.](#)  
Pijuan-Domènech A, Baró-Mariné F, Rojas-Torrijos M, Dos-Subirà L, Pedrosa-Del Moral V, Subirana-Domènech MT, Goya-Canino M, Cabero-Roura L, Garcia-Dorado D, Casaldàliga-Ferrer J.  
Am J Cardiol. 2013 Aug 15;112(4):590-3. doi: 10.1016/j.amjcard.2013.04.027. Epub 2013 May 22.  
PMID: 23706389 [PubMed - indexed for MEDLINE]  
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  5. [\[Contraception and congenital heart disease\].](#)  
Ladouceur M, Cohen S, Bidet M, Legendre A, Iserin L.  
Rev Prat. 2013 Mar;63(3):377-9. French.  
PMID: 23687768 [PubMed - indexed for MEDLINE]  
[Related citations](#)
  6. [\[Follow up of adults with congenital heart disease\].](#)  
Miltner B, Piérard L, Seghayé MC.  
Rev Med Liege. 2012 Jul-Aug;67(7-8):407-12. French.  
PMID: 22984760 [PubMed - indexed for MEDLINE]  
[Related citations](#)
  7. [Reproductive and contraceptive counseling received by adult women with congenital heart disease: a risk-based analysis.](#)  
Hinze A, Kutty S, Sayles H, Sandene EK, Meza J, Kugler JD.  
Congenit Heart Dis. 2013 Jun;8(6):628-34. doi: 10.1111/chd.12116. Epub 2013 Jun 13.

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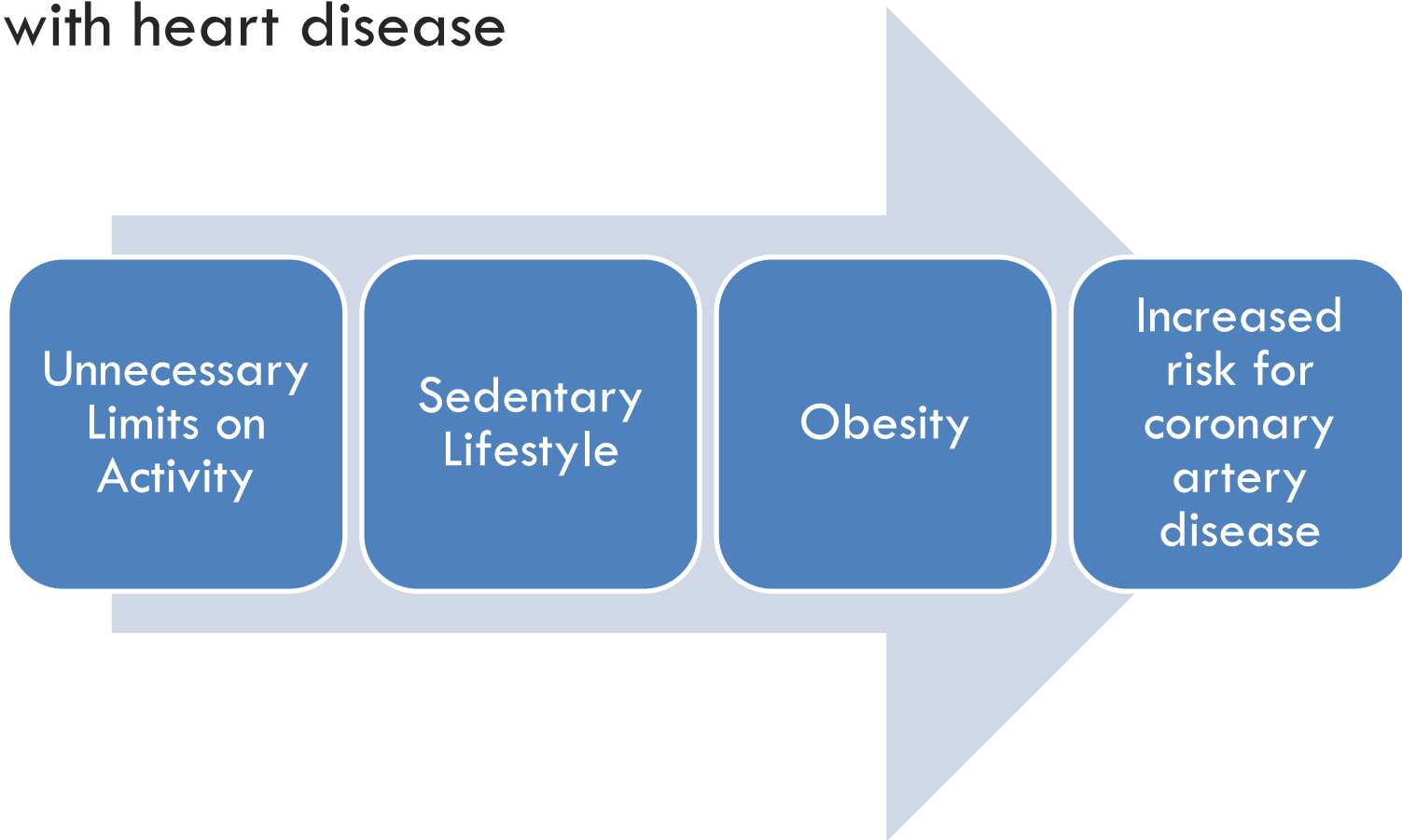
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# Should I restrict my child from activities?

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- A physical activity plan is required for all children with heart disease





# Conclusions

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- Use technology to keep a note of your child's heart condition
- Prepare for appointments
- Know your child's medical limitations
- Transition (ownership) of care is important for teens and young adults
- Medical preparation for trips/vacations

# Your family inspires me.

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