

# Upside Down Kids



Children with Special Needs

# Key Concepts

- ❖ Who are children with special health care needs (CSHCN)
- ❖ What are some complications and key interventions for selected special needs children
- ❖ There are significant physiological differences in children with Down Syndrome that may effect treatment modalities
- ❖ Assessing a child with Autism is challenging and frightening for everyone

# Case Scenario

You are dispatched to the local park for a child who has fallen from a tree. You arrive to see a large crowd around a small child on the ground. A woman is holding the child's head and talking quietly. There is a small amount of blood coming from the child's nose, and a strider is present. The child is not crying, but focusing on the woman's face. The woman calmly looks up as you approach and states, "This is my son, Adam, and he is special."

How will you manage this patient?



# Who are Children with Special Health Care Needs?

Children who  
are at risk  
for a chronic physical,  
developmental, behavioral or  
emotional condition and who  
also require health related  
services of a type or amount  
beyond that required by  
children generally.

(MCHB July 1998 - adopted by AAP October 1998)

# Increasing Population

- Increased survival rates from children suffering from critical injuries or disease.
- Advances in medical technology allow more children into the mainstream.
- More plentiful support services has decreased the time spent in hospitals for these children.

# Children with Chronic Illnesses - Special Considerations

- The child's baseline vitals may be different from others his/her own age.
- The child may have a decreased tolerance.
- The child may have received significant medical care prior to EMS arrival.
- The parent/caregiver can provide valuable information.

# Children with Chronic Illnesses

- Children with chronic illness may have medical emergencies for other reasons:
  - They may experience an unrelated illness or a traumatic injury.
  - They may suffer a sudden worsening of the underlying chronic condition.

# Delayed Mental Development

## Assessment Concerns

Use a sensitive approach:

- Ask for the child's name and use it.
- If necessary, use "special child" rather than terms like "retarded" or "slow."

# Ask the Parents/Caregivers

- Are there differences from normal abilities and behaviors now?
- Were these changes the primary reason for calling EMS?

# Pediatric Assessment Triangle--PAT



# Assessment - ABC

- Children with special needs are susceptible to airway obstruction.
- Technology-assisted children are at risk of device failure.
- Unable to compensate for even mild respiratory distress
- Signs of hypoperfusion may be masked because the baseline heart rate of the child may be accelerated.



# Always Urgent CSHCN

Child who has

- *respiratory distress or*
- *signs of hypoperfusion*

Transport ASAP with oxygen.

Additional assessment while en route.

# Ask the Parents/Caregivers

Determine the child's normal abilities and behavior in the following areas:

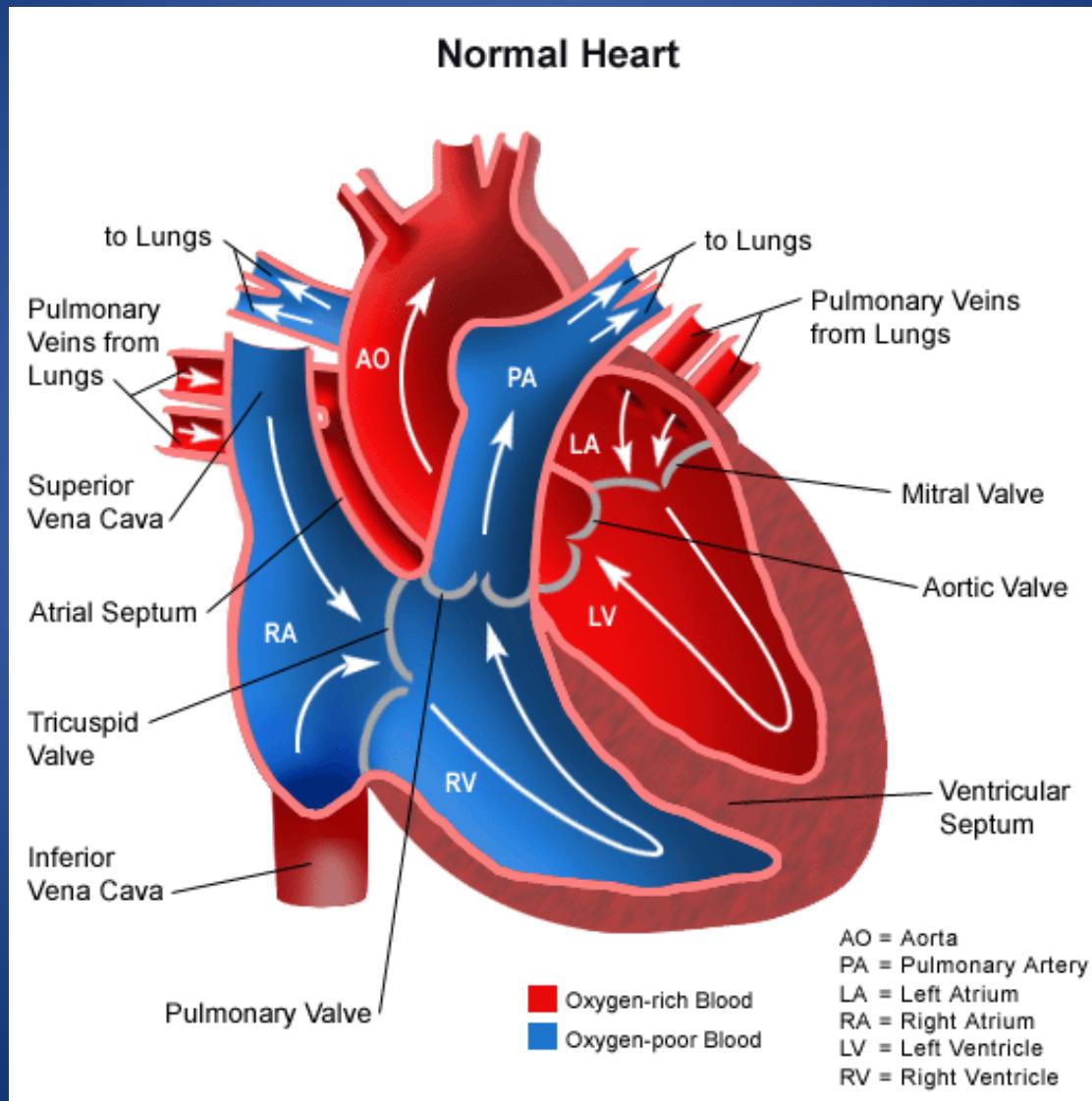
- mental status
- interaction with parents and strangers
- verbal abilities
- Physical development
- muscle tone and strength

# Congenital Heart Defects

# Congenital Heart Disease

- Children may be born with structural defects of the heart:
  - Heart valve problems
  - Arteries don't function correctly
  - Cyanotic heart disease
  - Electrical problem

# Normal Function of the Heart



# Tetralogy of Fallot-Four elements

Children with Tetralogy of Fallot exhibit bluish skin during episodes of crying or feeding.

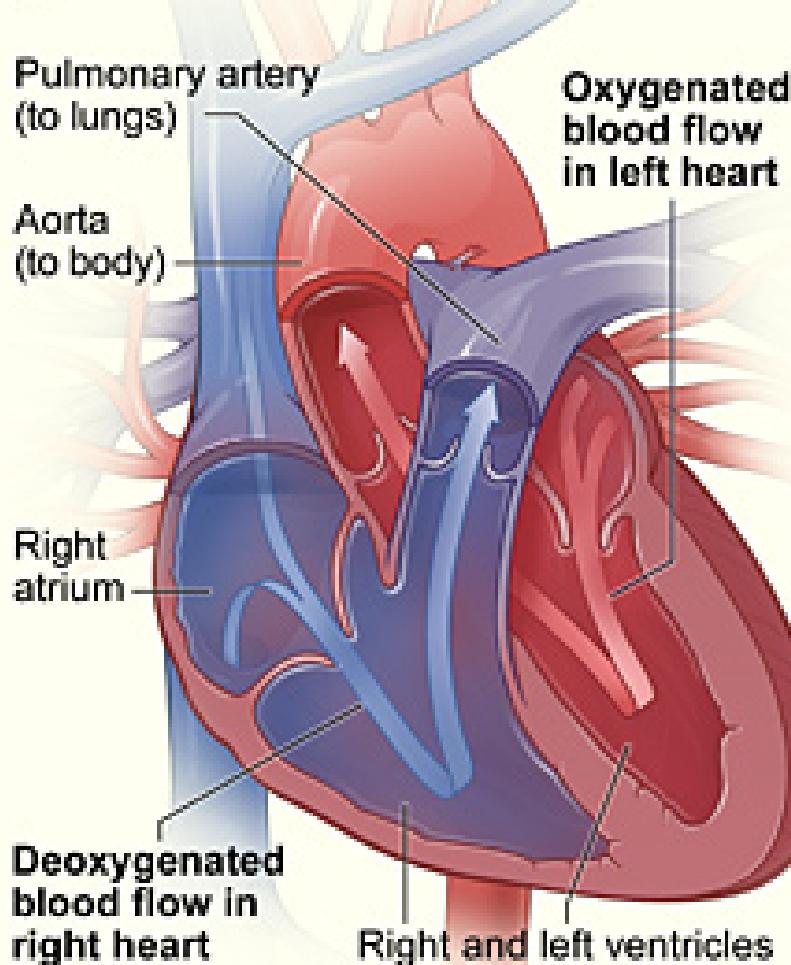


ADAM

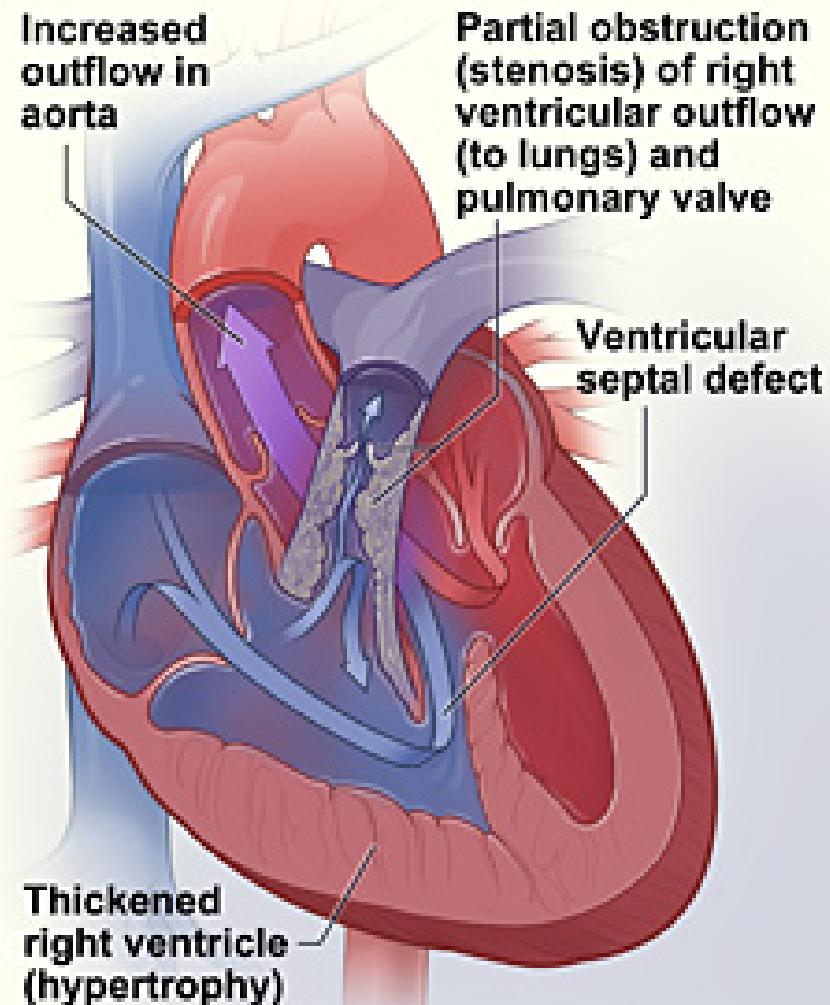
- Ventricular Septal Defect (VSD)
- Pulmonary stenosis
- Displaced or deviated Aorta
- Hypertrophy of Right Ventricle

# Normal Heart and Heart With Tetralogy of Fallot

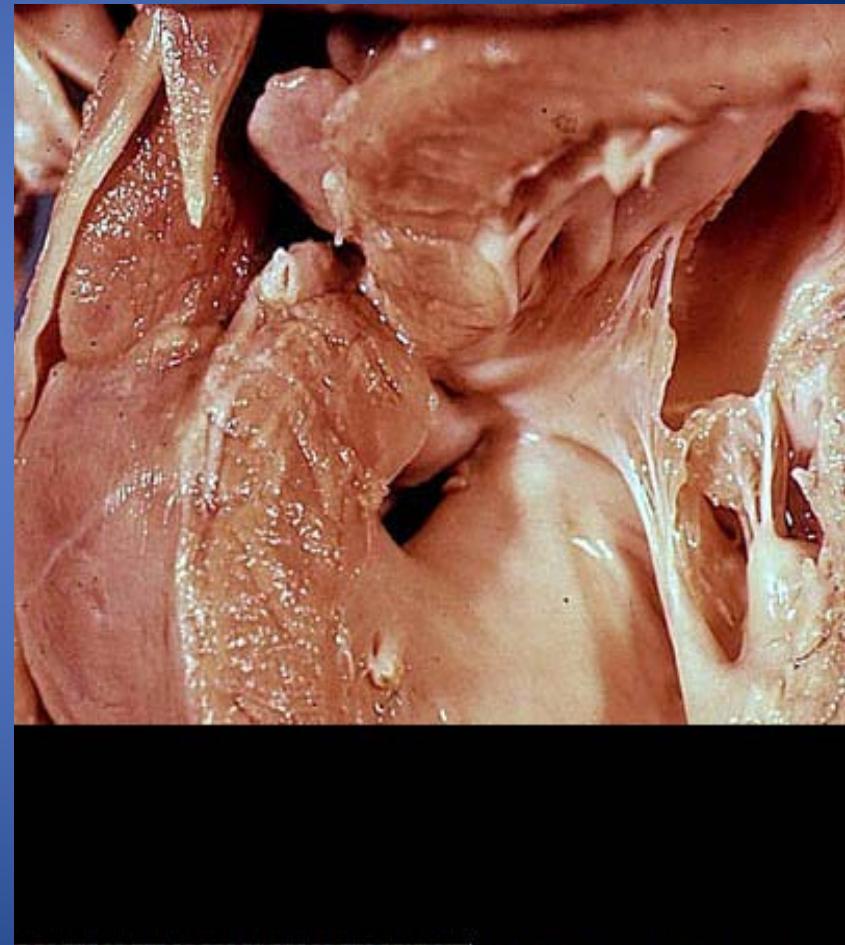
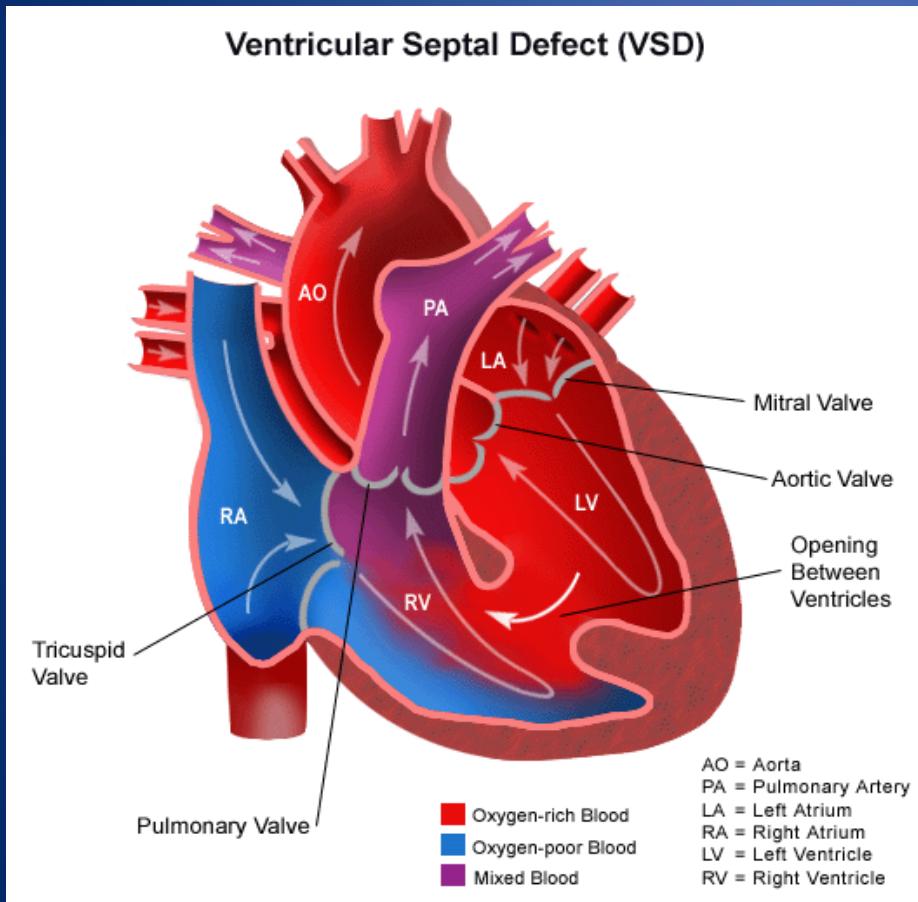
## A Normal heart



## B Heart with tetralogy of Fallot



# Ventricular Septal Defects (VSD)



# Atrial Septal Defect

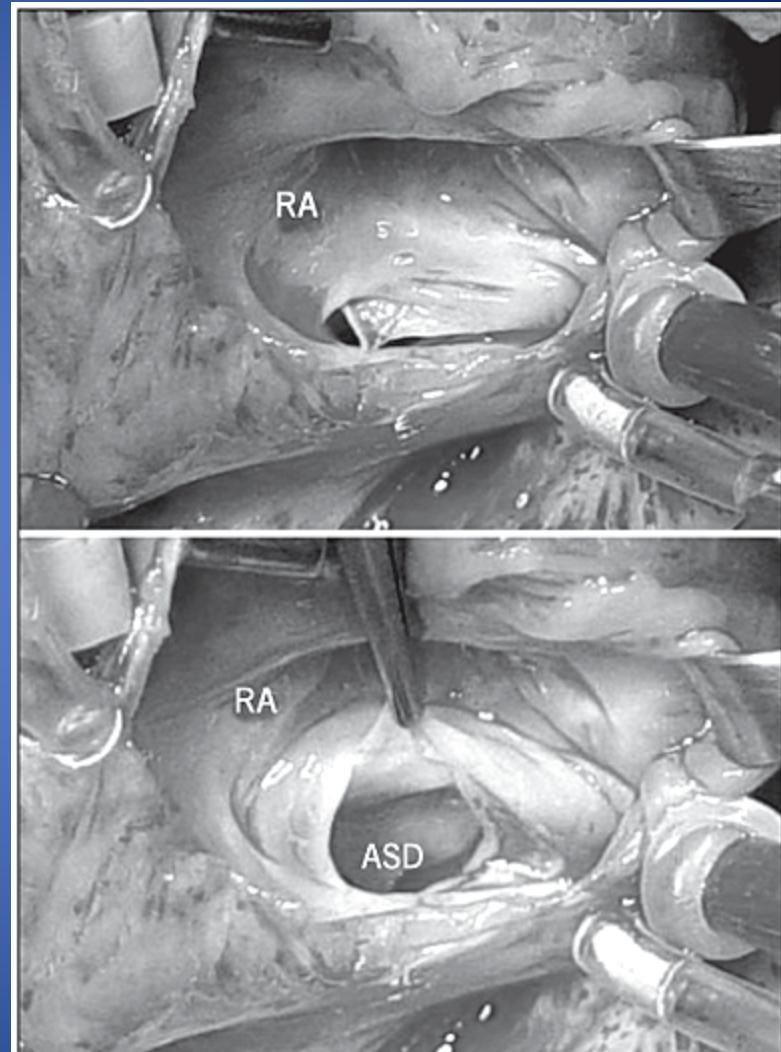
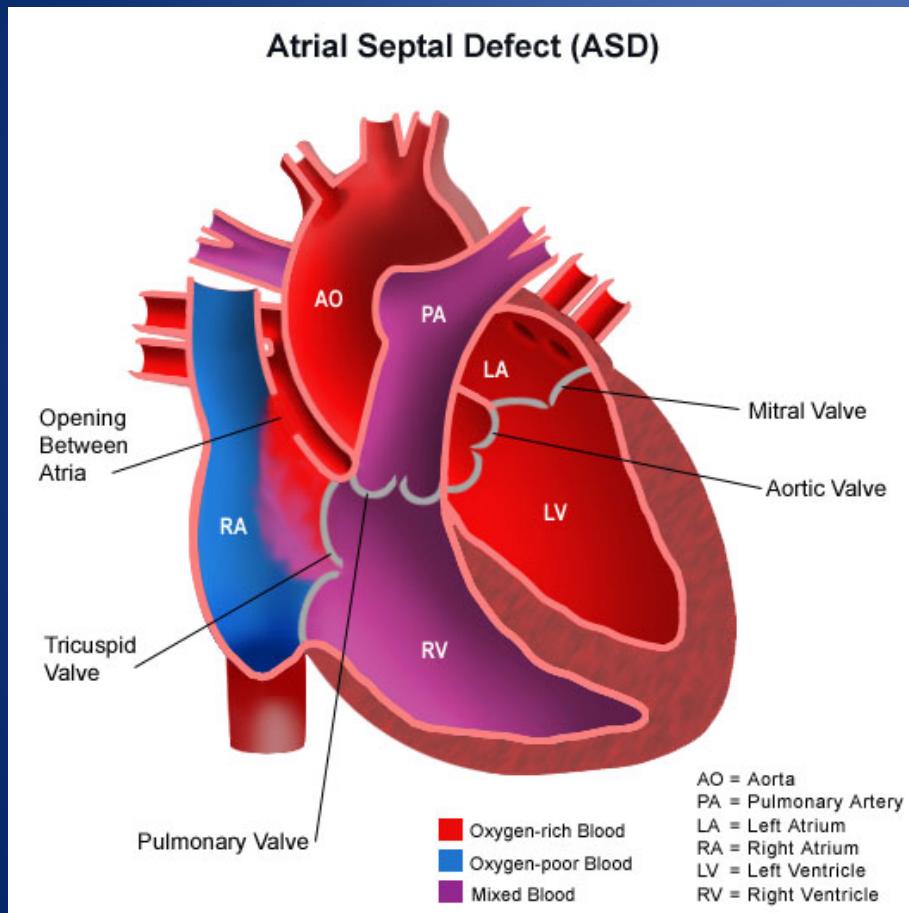
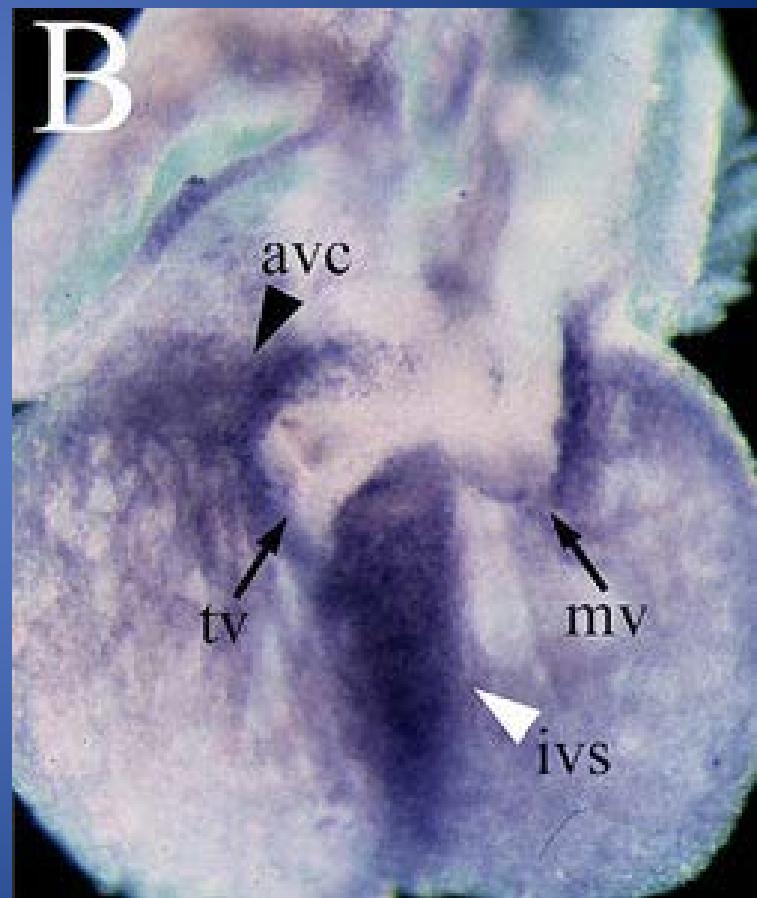
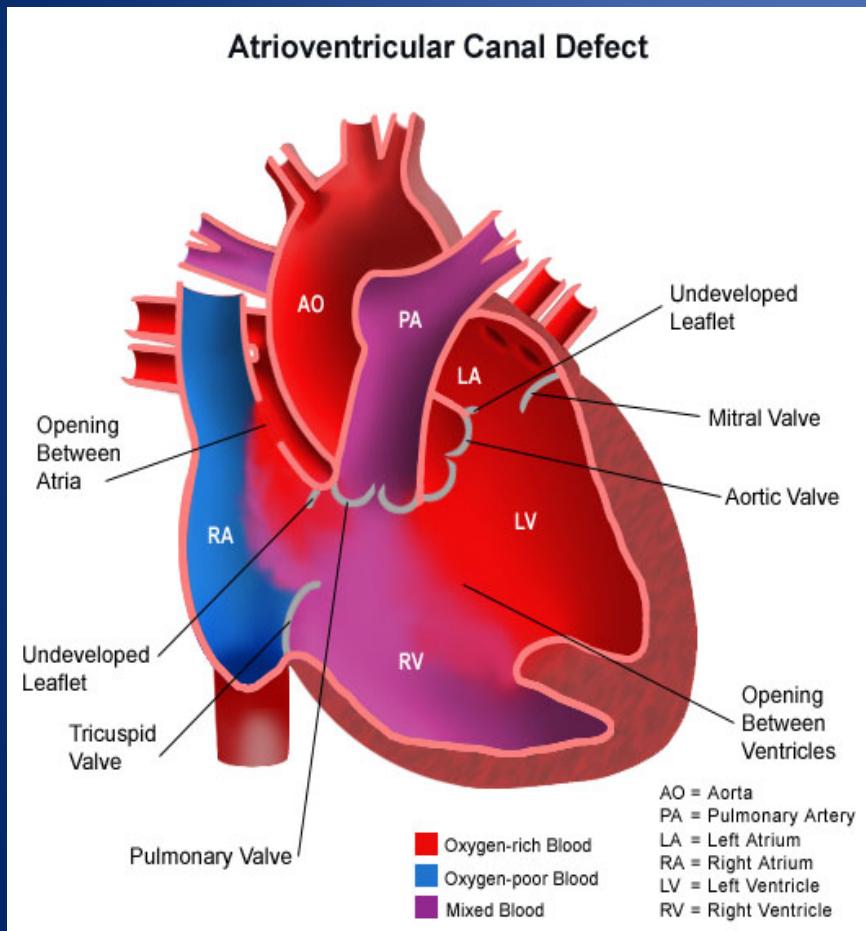


Fig. 2 – Aspect of the atrial septal defect 5 days after echocardiography monitored balloon atrial septostomy. B shows a pair of tweezers pulling the membrane of the torn oval fossa. RA- right atrium, ASD- atrial septal defect.

# Atrioventricular Canal (AVC)



# Symptoms common in Septal Defects

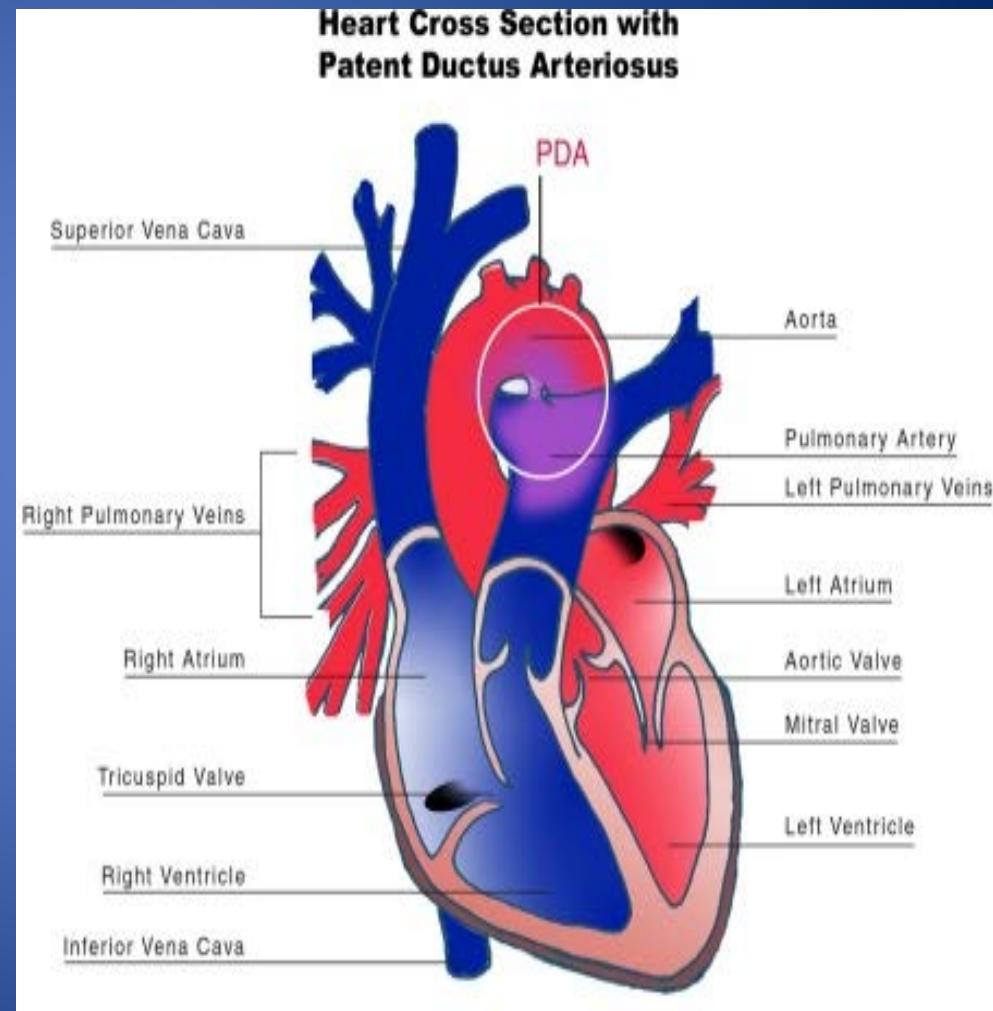
- Fatigue
- Sweating
- Pale/cyanotic skin
- Cool skin
- Rapid/heavy breathing
- Rapid heart rate
- Congested breathing
- Disinterest in feeding,
- Tiring while feeding
- Poor weight gain



# Patent Ductus Arteriosus--PDA

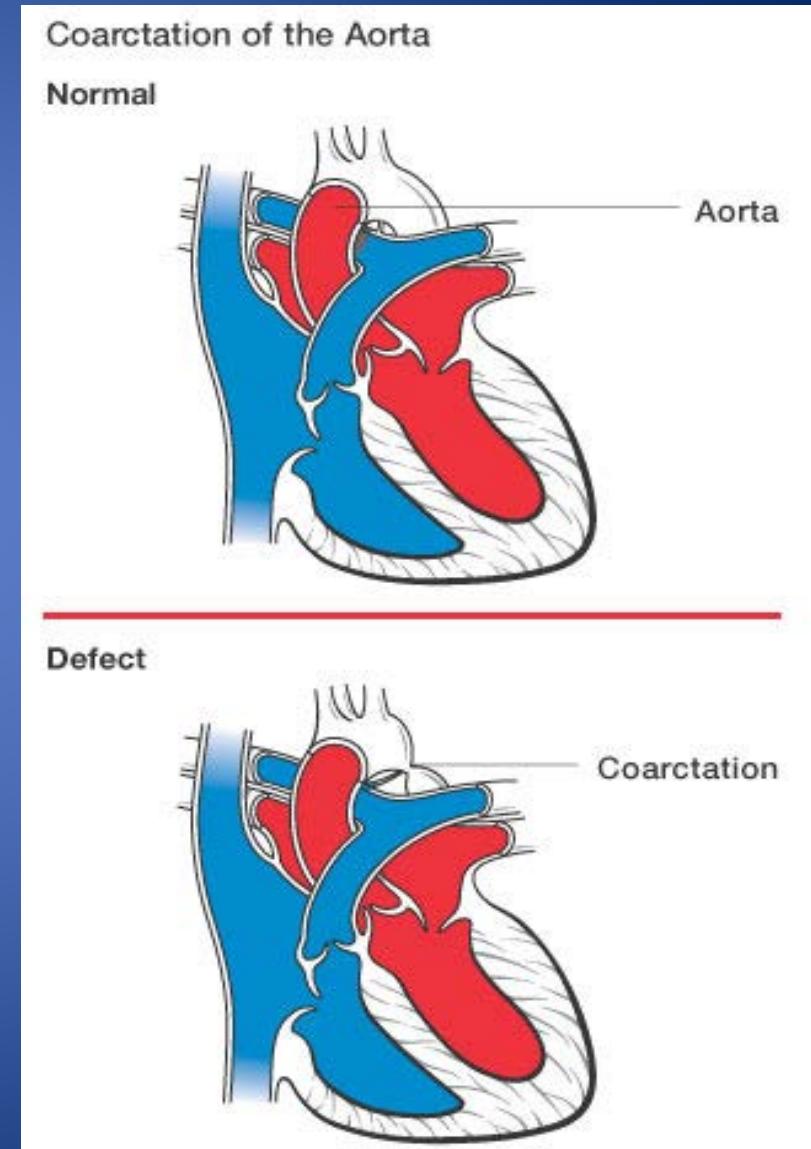
## Symptoms

- Bounding pulse
- Fast breathing
- Poor feeding habits
- Shortness of breath
- Sweating while feeding
- Tiring very easily
- Poor growth



# Coarctation of the Aorta

- Narrowing of the aorta between the upper-body artery branches and the branches to the lower body.
- Increase blood pressure in your arms and head  
Reduce pressure in your legs and seriously strain your heart.
- Aortic valve abnormalities often accompany coarctation.



# Congestive Heart Failure

## Common Symptoms in Children

- Failure to gain weight.
- Visible swelling of the legs, ankles, eyelids, face and abdomen.
- Fast breathing during rest, feeding or exercise.
- Shortness of breath or labored breathing.
- Fatigue.
- Frequent breaks while playing
- Nausea.
- Falling asleep when feeding or becoming too tired to eat.
- Congestion with cough
- Sweating.

# Congenital Heart Disease - Mgmt

## EMS Considerations

- These children will have low blood oxygen levels.
- Hypoperfusion (shock) is severely life threatening.
- Children with irregular pulses should be rapidly transported and constantly monitored.
- Medications may effect vital signs

# What is Autism?

*He acts aloof; withdrawn most of the time and doesn't seem to understand social cues. He seems overly obsessed with roads and can recite numerous facts related to highways. "Oh, he is just a quiet young boy, maybe a bit shy; a unique little boy", his parents say.*



Autism is one of five disorders that falls under the umbrella of Pervasive Developmental Disorders (PDD), a category of neurological disorders characterized by severe and pervasive impairment in several areas of development.



# Autism Spectrum Disorders

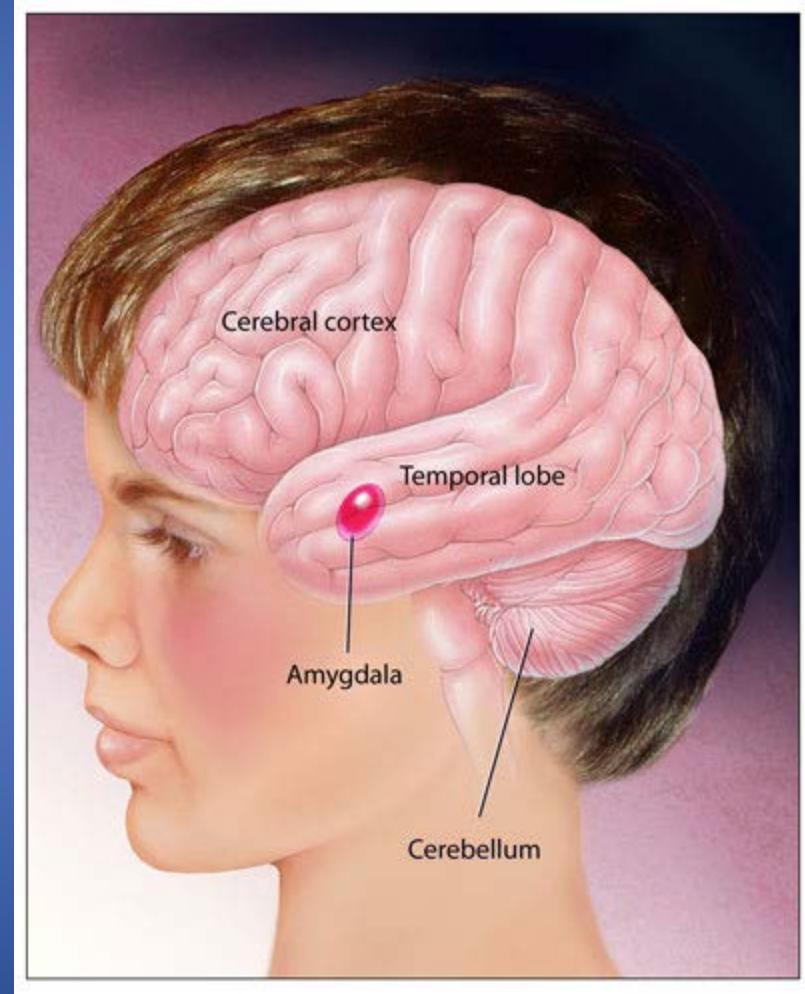
- Autism (Classical)—Most common
- Asperger Syndrome
- Rett syndrome--females
- Childhood Disintegrated Disorder
- Pervasive Developmental Disorder Not Otherwise Specified (PDD-NOS)



# What Causes Autism?

- Genetics & Environment?
- Disruption of brain development
- Serotonin neurotransmitters
- Irregularities in several regions of the brain

*The theory that parental practices are responsible for autism has now been disproved!*



# Autism Checklist

1. Difficulty in mixing with other children
2. Inappropriate laughing and giggling
3. Little or no eye contact
4. Apparent insensitivity to pain
5. Prefers to be alone; aloof manner
6. Spins objects
7. Inappropriate attachment to objects
8. Noticeable physical overactivity or extreme underactivity
9. Unresponsive to normal teaching methods
10. Insistence on sameness; resists changes in routine
11. No real fear of dangers
12. Sustained odd play
13. Echolalia (repeating words or phrases in place of normal language)
14. May not want cuddling or act cuddly
15. Not responsive to verbal cues; acts as deaf
16. Difficulty in expressing needs; uses gestures or pointing instead of words
17. Tantrums - d
18. Uneven gross/fine motor skills

# Interactions

- Human contact
  - Avoid eye contact
- Difficulty understanding and talking about feeling
  - Resist being held or cuddled by parents or guardians



# Interactions

# Toys

Focuses on one specific part  
versus entire toy

- Spinning wheels of a toy truck
- Watching traffic lights, fans, running water or repeatedly flush toilet

Unique toy preferences-  
lecting rubber bands,  
paper clips or pieces of paper



# Reactions to Stimuli

- Extremes in sensory processing and response
  - Aggressive, self-injurious or violent
- Behaviors associated with autism
  - Individual's inability to integrate and respond



# Reactions to Stimuli

- Routines:
  - Disruptive behavior; outbursts
- Senses:
  - Abnormally over- or under-active
  - Textures
  - Odors
  - Normal sounds



# Signs and Symptoms

- Inability to maintain eye contact with another person
- Infants may not want to be cuddled and show minimal social imitation
- Toddlers and older children unaware of other children—  
inattentive
  - $\frac{1}{2}$  of all children with Autism are nonverbal
- Do not adapt well to any change in their routine.
- Repetitive Behaviors
  - rocking or spinning in circles
- Abnormal behavior
  - Hand flapping
  - Inappropriate sexual behavior in public
- Echolalia—repeating what was just asked or heard

# Key Parts EMS Response

**Recognition**--repetitive motions, avoids eye-contact, unusual sensory response

**Assessment**--work from distance, communicate, calming, limit contact

**Identification** --personal, caregivers

**Anxiety Management**--reduced sensory stimulation, communication before procedures

# Prehospital Assessment

- Vital Signs---as allowed by behavior
  - Skin signs to determine perfusion status if patient is acting out
- Head-to-toe
  - Be alert to signs of trauma (self-injury)
  - Self-inflicted and abuse can be difficult to distinguish



# Prehospital Assessment Tips

Tip 1. Visual-disillusion

Tip 2. Use a quiet, sing songy or Robotic voice.

Tip 3. Carry a distractor

# Prehospital Assessment Tips

Tip 4. Carry earplugs/cotton

Tip 5. Be patient, especially when they are stimming

Tip 6. Autistic child may not want to come out from under a bed in a fire situation

➤ *Pearl: Do NOT put an IV in the middle of the arm, as it is extremely sensitive in autistic people; other sites on the arm like the side of the wrist they sometimes will not feel. Wrap up the site to prevent accidental infiltration or removal*

# Prehospital Management

- Nature of the incident
  - Normal treatment modalities
  - Altered treatment methodology
- Altered LOC
  - Investigate and treat potential causes
    - Hypoglycemia
    - Trauma
- Violent /Abnormal physical behavior
  - Parental assistance
  - Restraints
  - Follow local protocols
- Medication administration
  - Oxygen to chemical restraints
  - Confirm with medical control
  - Follow local protocol

# Autism Summary

Autism is a complex disorder. A good understanding of what can be expected when caring for an autistic patient is vital to the successful management. Ensure thorough assessment and optimal treatment is provided.

*Parents are invaluable!!!*

# Down Syndrome

Down Syndrome:  
a genetic  
condition that  
causes physical  
and intellectual  
development  
delays in  
individuals





# History of Down Syndrome



Jonathan Langdon Down is best known for his study of a small group of children with similar physical and mental characteristics in 1866. When Down was the first medical superintendent at Earlswood Asylum, he devised the classification of "Mongolian Idiot," which later became Down's syndrome. His study would later lead to the discovery of an extra chromosome or the 21st chromosome. Down is also known for his ethnic classification of developmental disabilities. His paper "Observations of an Ethnic Classification of Idiots," discusses his belief in race oriented taxonomy.

# Down Syndrome

1 in 800-1000 live births

47 chromosomes

(23 pairs + 1)

Most frequently occurring  
chromosomal disorder

Not related to race,  
nationality,  
religion or socioeconomic  
status

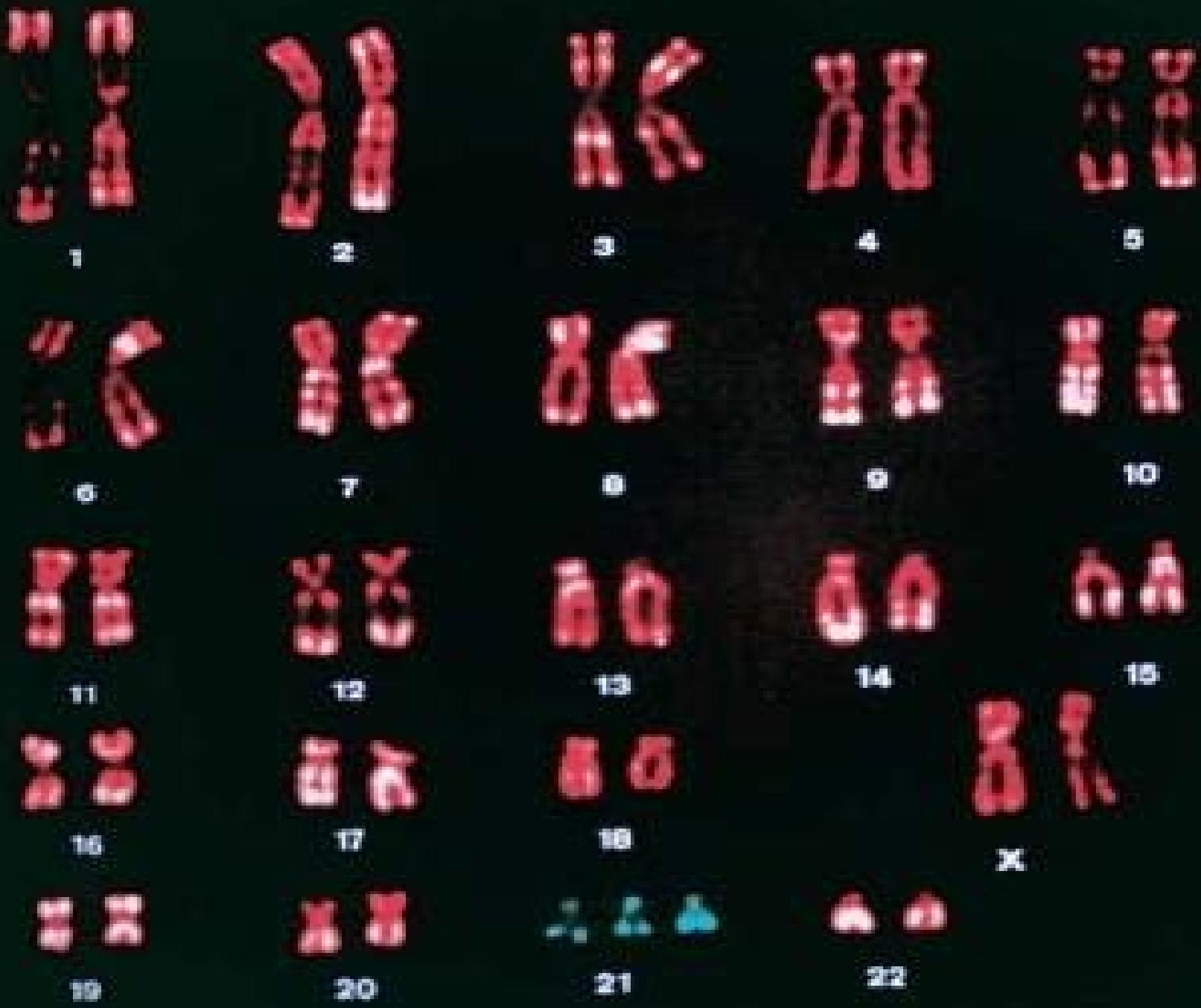
Individuals with Down  
syndrome are more  
like others than they are  
different.



# Types of Down Syndrome

3 chromosomal patterns resulting in Down syndrome.

- **Trisomy 21 (nondisjunction)**—faulty cell division-most common
- **Translocation**- 3% to 4% of all cases- characteristics of Down syndrome.
- **Mosaicism**—mixture of two types of cells (46 or 47 in some) 1-2% of all cases





# Myth Busting

**Myth**--Most Down's children are born to older women (over 35)

**Fact**--80 percent of babies with Downs are born to women under 35

**Myth**--All people with Down syndrome look and act the same

**Fact**--People with Downs share many physiological similarities—mostly they look like their families

# Myth Busting

## Myth

People with Down Syndrome are always happy

## Fact

People with Down syndrome have bad days just like everyone else....

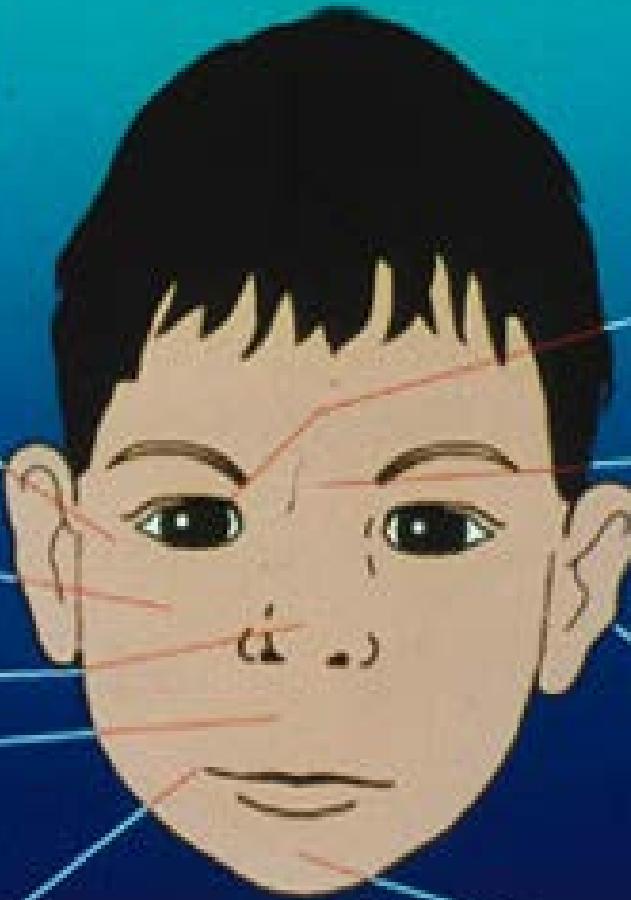


# Anatomy of Down Syndrome



## Discriminating Features

short palpebral fissures  
flat midface  
short nose  
indistinct philtrum  
thin upper lip



## Associated Features

epicanthal folds  
low nasal bridge  
minor ear anomalies  
micrognathia

In the Young Child



Trisomy 21 - Hand Features



# Health Issues

Septal Defects

Cataracts

Gastrointestinal

Blockages

Esophageal Artesia

Duodenal Artesia

Hearing Problems

Glue Ear

Infections

Sleep Apnea

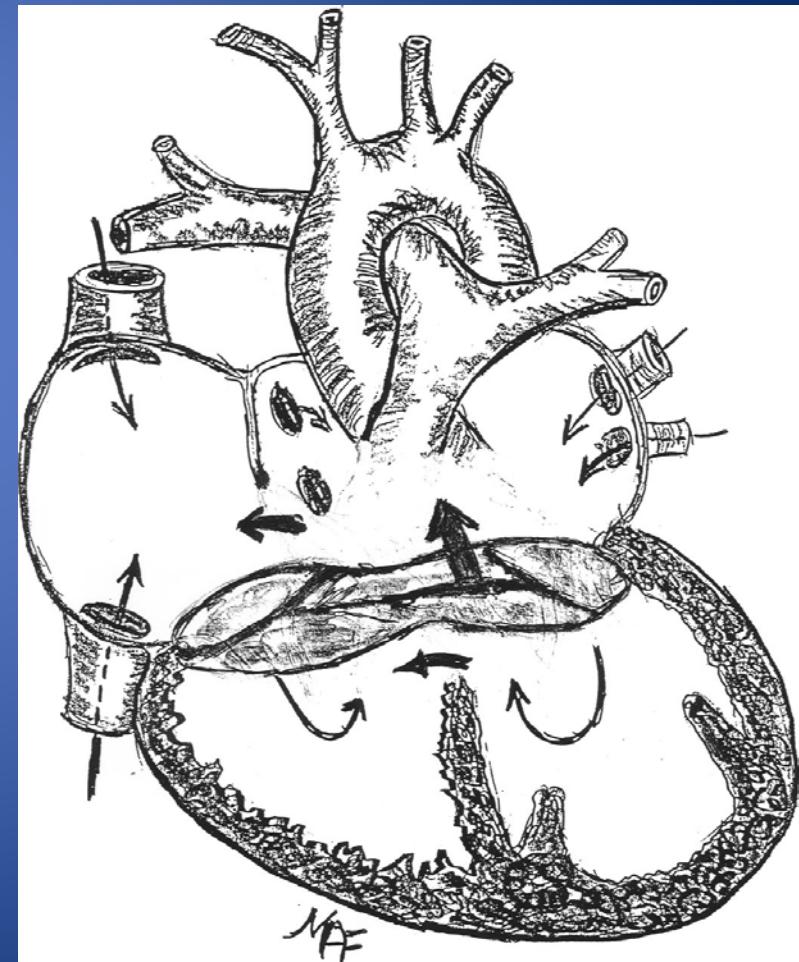
Hypothyroidism

Acute Lymphocytic  
Leukemia

Atlanto-axial instability

# Types of Congenital Heart Disease in Down Syndrome

- Atrioventricular Septal Defect
  - AVSD, AV-canal, ECD
  - 70% of all AVSD's in DS
  - 60% of CHD in DS
  - 2.8% of CHD in non-DS
  - AVSD constitutes spectrum of defects
- Atrial Septal Defect
- Ventricular Septal Defect
- Tetralogy of Fallot
- Patent Ductus Arteriosus



# Hypotonia

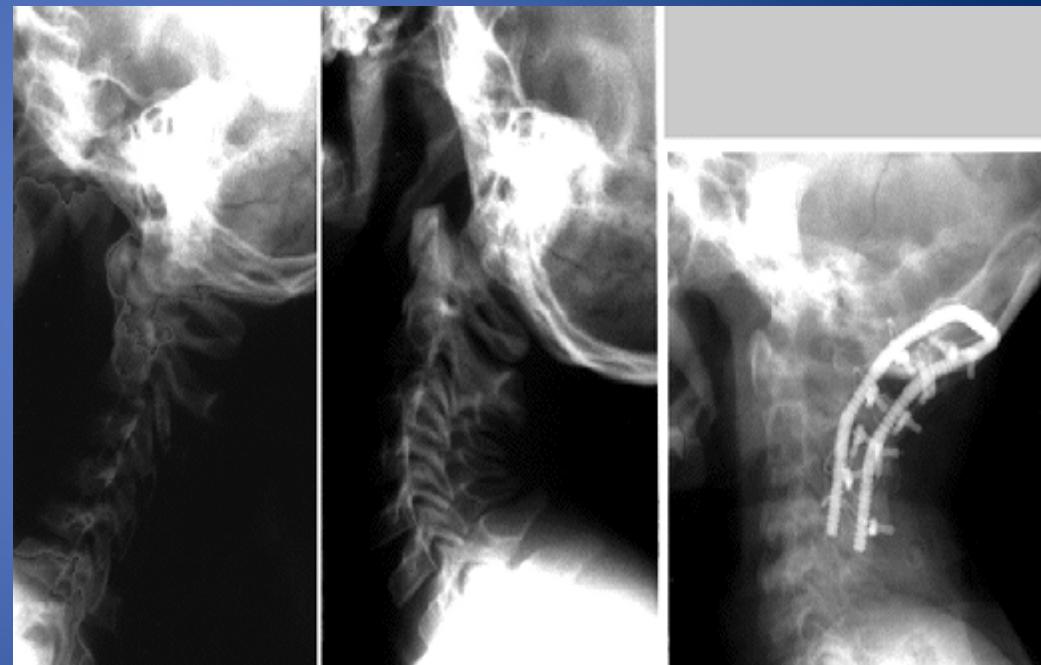
## Low Muscle Tone

- Virtually all infants
- Flexor group-joint
- Mild-moderate-severe
- Lagging head
- Arching back
- Tire easily
- Adopt alternate movement patterns



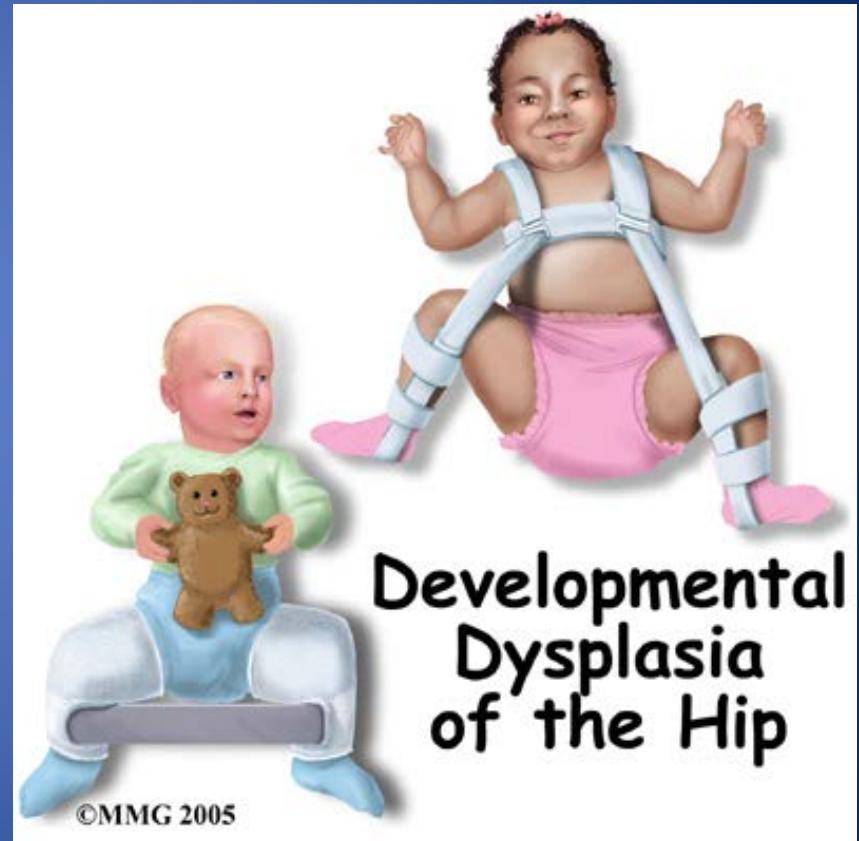
# Atlantoaxial Dislocation

- Cause- Hypotonia
- Ligaments of C1 &C2
- Risk of Spinal Cord compression/injury
- 10-20% in Down's
- Commonly no symptoms
- Limit “High Risk” activity



# Hip Dislocations

- Abnormal collagen
- Ligament laxity
- 5-8% Hip Abnormalities
- Hip Subluxation
- Malformation of acetabulum
- Found at 3-13 years
- Limp
- Hip cast/surgery



# EMS Challenges

- Airway Management
  - Intubation
- Management
  - Atlantoaxial instability
  - Immobilize if:
    - Unconscious
    - Awake enough to complain of neck pain
    - Weakness even WITHOUT evidence of cervical trauma

*Pearl: Do Not hyperextend the head as spinal cord compression can result !!!*

# Scenario Revisited

A woman is holding the child's head and talking quietly. There is a small amount of blood coming from the child's nose, strider is present. The child is not crying, but focusing on the woman's face. The woman calmly looks up as you approach and states, "This is my son, Adam, and he is special. He has Down Syndrome."

What are your concerns?  
How would you manage him?  
Does this effect your transport decisions?



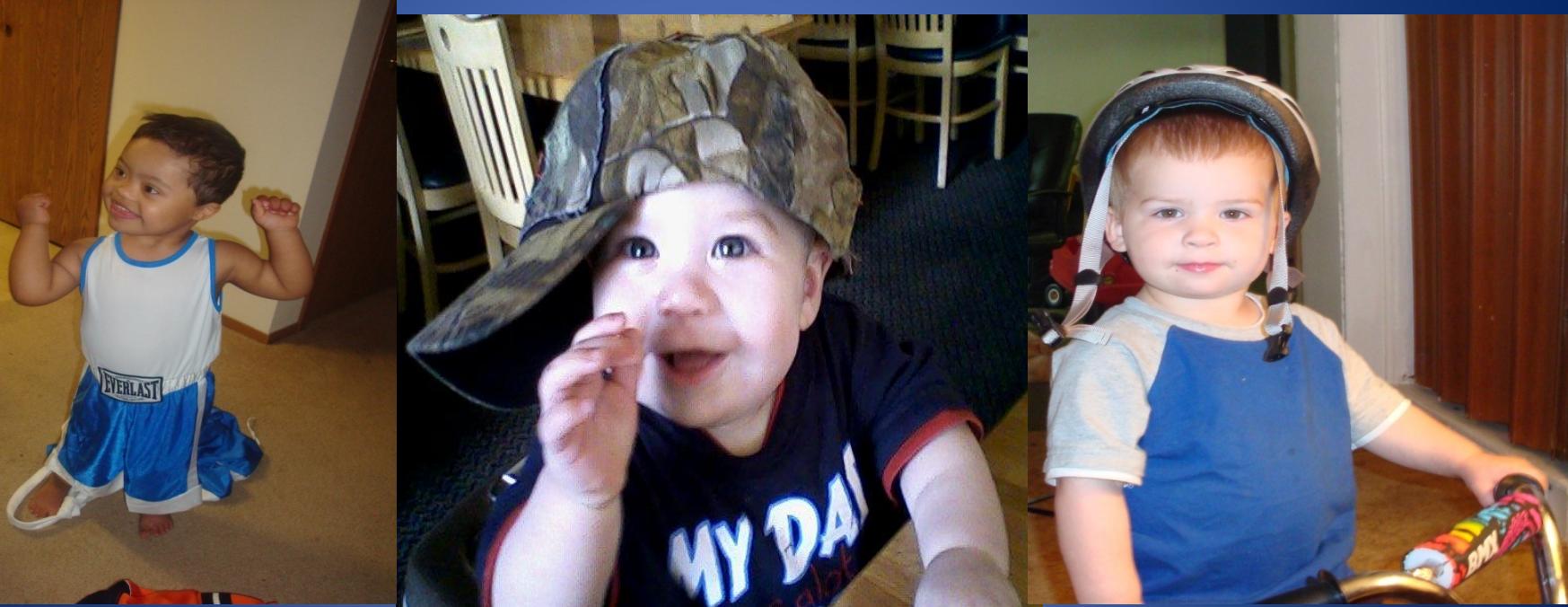
**Myth**  
People with Down  
syndrome  
can be trained  
but can't learn

**Fact**  
Down syndrome causes  
delays,  
but people with  
Downs can and do learn

# Final Thoughts

- Modify Initial Assessment steps as warranted
- Focus on any condition of the airway, respiratory or circulatory system.
- Take nothing for granted.
- Parent/caregiver is key in assessment.

*All people need to be viewed for the person they are first and foremost, not for the label attached to them!*



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