

Sotos Syndrome: Early Intervention

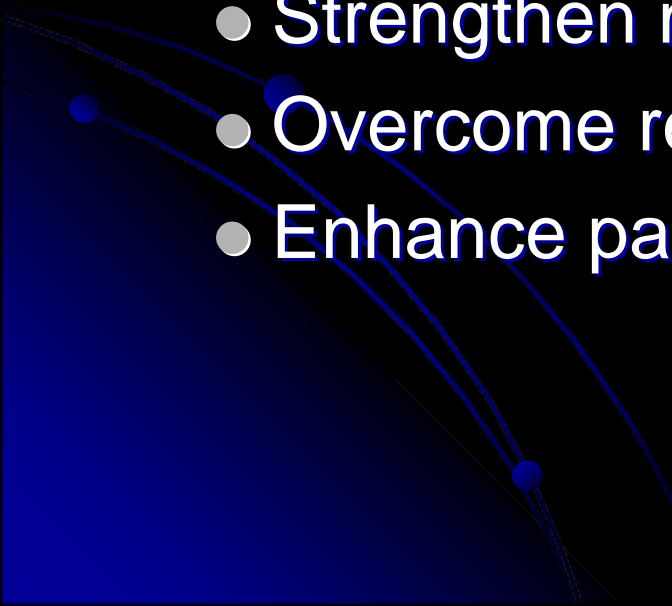
Motor, Cognitive and Behavioral

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Physical Therapy

- Intent:

- To maintain full range of motion
 - Enhance balance
 - Strengthen muscles
 - Overcome reflexes
 - Enhance parent-child interactions
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Prone Sequence



Birth: arms and legs flexed



2 mo: head/shoulders up



3 to 4 mo: up on forearms



4 to 5 mo: up on wrist

Postural Response

Head righting



4 months

Equilibrium



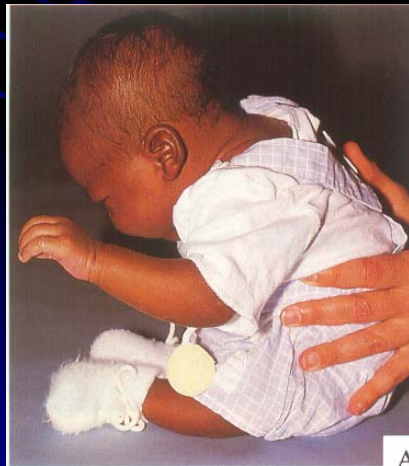
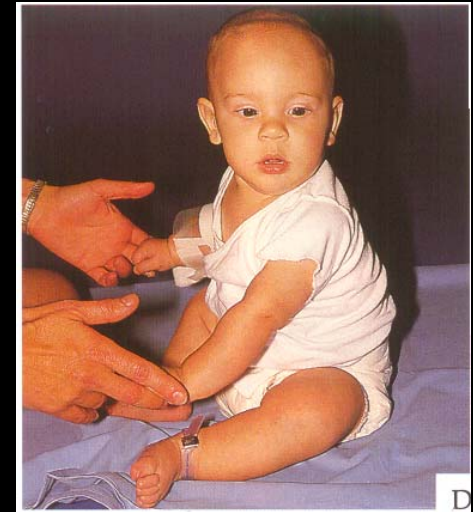
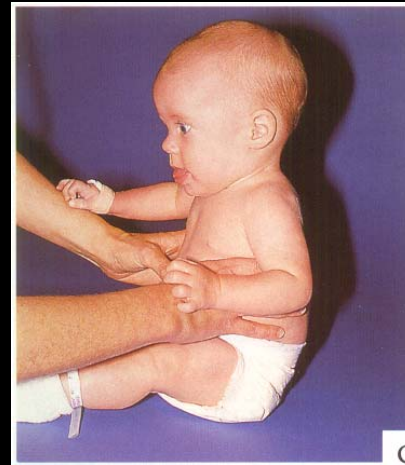
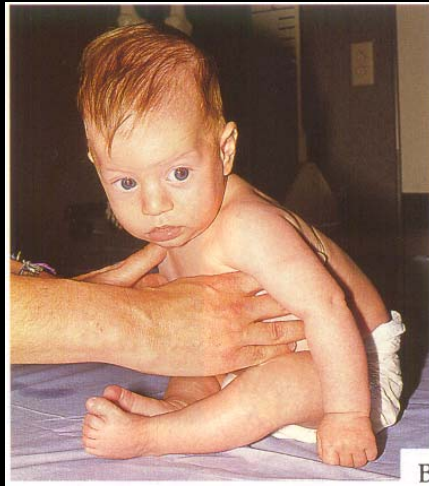
Anterior 6 mo
Lateral 8 mo
Posterior 10 mo

Parachute



10 months

Sitting Sequence



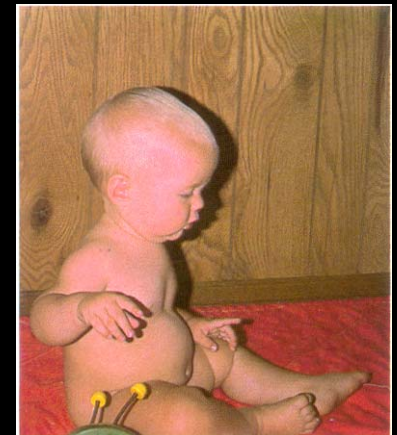
2 to 3 mo

3 to 4 mo

5 to 6 mo

1 to 2 mo

7 to 8 mo



Walking Sequence



Crawl 7 - 10 mo



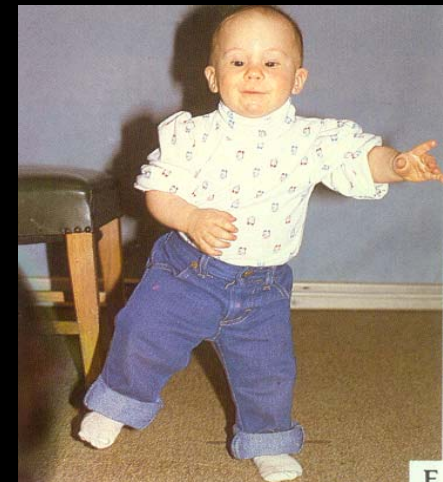
Bear walk



Cruise 8 - 11 mo



Commando Crawl 6 - 7 mo



Walk 11 - 15 mo

Primitive Reflexes -1

Moro

Appears birth
Disappears 4 mo



Phase 1



Phase 2

Primitive Reflexes -2



Hand
Grasp

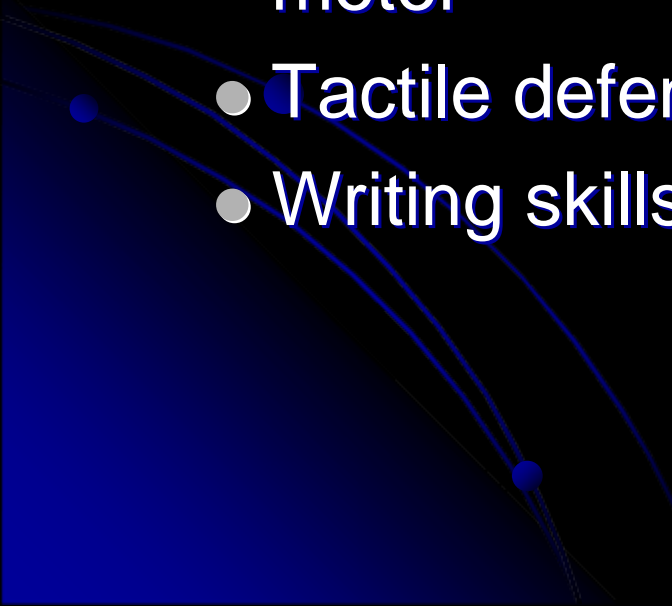
Appears birth
Disappears 3 mo

Asymmetric Tonic
Neck Reflex (ATNR)



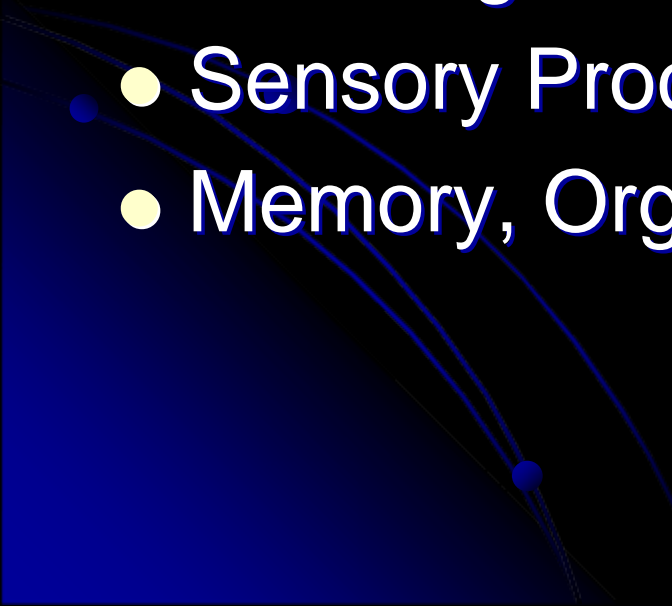
Appears 2 wks
Disappears 6 mo

Occupational Therapy

- Intent:
 - Eye-Hand coordination
 - Feeding issues
 - Drooling....lip closure, strengthening oral motor
 - Tactile defensiveness
 - Writing skills
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Neurosensory Integration: Specialized Occupational Therapy

- **The integration of our visual, auditory and balance systems lays the foundation for:**
 - Learning Abilities
 - Sensory Processing
 - Memory, Organization, Concentration
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Hypotonia in Sotos Syndrome

- Infants and children have decreased tone, not weak muscles. Brain maturation is delayed, so signals to muscles from the brain develop later. Coordination, balance, crawling, walking are later.
 - Therapy does not speed the process, it prepares the child to be ready when the pathways are functional.
 - The delay in Sotos is often a year or greater, but it does develop
 - Speech is a motor function-it is also delayed but receptive language is closer to normal, children understand more than they can articulate.

Hypotonia

Symptoms

- Symptoms vary:
 - decreased muscle tone, muscles feel soft and doughy, but normal mass
 - ability to extend limb beyond its normal limit
 - failure to acquire motor related developmental milestones (such as holding head up without support from parent, rolling over, sitting up without support, walking)
 - problems with feeding (inability to suck or chew for prolonged periods)
 - shallow breathing
 - mouth hangs open with tongue protruding (under-active gag reflex)



Speech Therapy beginning at 12 months-greater frequency

- Early intervention for language, may require signing or pictures while working on speaking
- Receptive language is a better measure of cognitive ability and is ahead of speech.
 - 1-3 step commands at 18 months to 2 years demonstrates cognitive skills
 - Functional language....pointing, pulling, bringing the object.....not tantrums
 - Responding to no, yes, smiling appropriately

Frequency of PT and OT

- Studies show outcome is determined by parents/caregivers therapy frequency:

NOT by the amount of time with the physical therapist or occupational therapist

- The parents should learn from the therapist and do the exercises at home. Also daycare workers and other caregivers should be trained.

- And

- *Parents need to be trained in lifting to preserve their backs.

Cognitive Delays

- Variable in each person with Sotos Syndrome
- Best assessed after 5, before involves motor delays
- Testing is a point in time, not always predictive of adult abilities
 - May not measure concrete memory or social skills

Learning disabilities requires specific types of testing such as a Woodcock-Johnson test

Behavioral Issues

- Work with the school, include in the IEP
- Consistency: Same strategies at home and in school or daycare
- Concrete limits, expectations
 - consequences need to be immediate such as time out
 - Consistent consequences
 - Reward good behavior when observed

Issues in early Childhood

- Hyperactivity not necessarily ADHD, may be age or gender related
 - Lack of Language and Frustration
 - Stereotypic/compulsive behaviors
 - Tantrums
 - Inability to follow commands, off task
 - Poor sleep patterns
 - Aggressive behavior

Issues

- ADHD/ADD.....generally not diagnosed or treated with medications before 5 years old, some exceptions.
- Hand flapping, twirling, self abusive behavior....common in all children but not after 3-4 years of age
- Lining up cars or toys, focusing on one activity.....common till 5 years old

School Age Children

- Depression and anxiety:
 - Recognizing differences between themselves and friends, low self esteem
 - Situational....loss of a relative, divorce, lack of friendships
 - Inherited / Physiologic.....may need therapy and only when medically diagnosed, medication may be necessary

School Age

- Oppositional Defiant Behaviors....often associated with Puberty, can be very aggressive
- Learning Disabilities.....confused with ADHD or ADD, off task but because they can't do it.....consider LD testing
- Masturbation....normal,going to happen, but “where” is the issue.

School Age

- Phobias.....fear of being bullied, not wanting to participate in group activities.....need to encourage socialization. Success in adults is approximately 50% due to social skills.
- Lack of motivation.....encourage peer interaction, inclusion and being with chronological role models. Rarely allow school to hold the child back a year.

Health Professionals: who to seek for help?

- Psychologist.....Behaviorally trained for acting out, etc. School trained for testing of LD or other processing problems
- Social work....helpful in placement and obtaining supports
- Physician.....General health and referrals
- Psychiatrist.....tends to be oriented toward medication for treatment

Transition

- 14 to 16 years of age school and parents should be doing planning for adulthood. This includes assessing driving skills and potential living independence.
- This causes anxiety and stress.....may see mood disorders, separation anxiety, “clinginess”, or depression (Situational)

Adults

- Plan for some independence....living on their own or supervised.
 - Start looking at options early, may take years to get into group home or supervised living
- Vocational or College with support
- Trust funds....established for a specific purpose, not open to paying for government provided services

Questions?



Thanks.....Bruce