Down Syndrome.....Children with Special Needs

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This Presentation is an overview

- More detail and specifics will be covered in the Panel discussion next.

- There may be some overlap but the focus of this talk is maximizing the quality of Life for individuals with Trisomy 21.
Disability versus Ability

- From the time of diagnosis the bar should be set high and expectations should be individualized.
- The literature can be misleading since many studies were done when individuals with Down Syndrome were institutionalized and underestimated potential.
Early Issues for Children with Trisomy 21

- Hypotonic
  - Poor suck
  - “Floppy”
  - Poor head control
  - Eyes wander
  - Palmar crease
What is muscle tone?

- True muscle tone is the inherent ability of the muscle to respond to a stretch.
- A muscle's tone is a measure of its ability to resist passive elongation or stretching.
- **Not** synonymous with strength:
  - Tone = resting level of contraction
  - Strength = volitional force that can be generated
Muscle Tone

- Tone is determined as the cumulative input (positive and negative) of signals into the anterior horn cells.
Cardiac Findings

- Heart Problems....1/3 have significant involvement requiring surgery, 1/3 have Holes/ASD/VSD sometimes requiring later surgery, 1/3 have a murmur to be followed....all require an echocardiogram after birth
Early Issues for Children with Trisomy 21

- Gastrointestinal problems
  - Hirshsprungs Disease (5%)
  - Constipation
- Dry Skin
- Pneumonia, Otitis Media (Pneumococcus most common)
- Decreased antioxidant activity (superoxide Dismutase Deficiency)
May need Multivitamin

- Because of decreased antioxidants may need a multivitamin with Beta Carotene, Vitamin C and E.....six months to one year to start

Do not need herbal preparations or anti aging drugs

- Need appropriate proteins and fats (Next session)
Physical issues in Infants with Trisomy 21

- Flat Feet….do not need inserts, a good sneaker is best
- Small to absent sinuses….chronic “runny nose”
- Small mouth…not large tongue
- Strabismus….true “crossed eyes”, after 1-2 years of age…may need surgery
- Short, Shovel shaped fingers….3 and 4 fingers are equal length
- Diastasis Recti….gap in abdominal muscles, normal by 2-3 years old, but tendency for protuberant abdomen
- Cutis Marmorata….prominent veins
- Shorter stature than family heights
Physical Issues in Down Syndrome

- Large Fontanelle....soft spot. Will close later. No danger
- Unstable neck...odontoid may not articulate well with the skull....evaluate by XRay at 5, may have to limit tumbling
- Sitting and walking may be delayed
Begin Early Intervention

- As soon as the diagnosis is confirmed, contact the nearest school in your district and request Early Intervention Evaluation/Treatment
- Usually this will be done in the home for the first 3 years, then Center based ½ day programs till Kindergarten
- PT, OT, Special Educator, and Speech (at 12 to 18 months)
Advantages of Early Intervention

- Parental training, and bonding
- Getting things ready when the Hypotonia improves....sitting, walking, talking
- Developing social skills
- Preparing the child for an inconclusive education with peers
Behavioral Issues

- All infants cry, picking them up may increase it, cuddling and holding when they are good is a better reinforcement.
- Infants need to sleep on their backs in their room or a separate bed from Mom and Dad.
Developmental Issues in Trisomy 21

- Language Delays....
- Decreased hearing from Chronic Otitis Media....may require tubes after 3 infections, to improve articulation
- Gross and fine motor delays may persist...Hypotonia
- Poor weight gain initially then increased weight gain potential
- Underestimates of intelligence....due to motor delays
Delayed Speech

- Processing and understanding speech is close to chronologic age
  - Speak normally to your child, stimulate speech
  - Do word and picture associations
  - Use **NO** when necessary
- Articulation may be poor due to motor delays
School Years

- Socialization with Peers
- Making friends
- Participating in activities, possibly sports (Special Olympics), definitely recreation
- Classroom: Inclusive
  Needing special help in some subjects (resource room), continued speech therapy, and “homework” with the family
Issues for Children with Trisomy 21 as they Mature

- Sexuality
- The “difficult Teenager”
- Peer pressures / acceptance
- Hygiene
- Obesity and exercise
- Transition from education to occupation.....planning for the future after 21
Adults with Trisomy 21

- Majority are infertile, but marriage is a possibility

- All adults need routine medical care
  ....blood work, cholesterol screening, blood pressure, ekg, colonoscopy..... depending on age

- Increased risk for leukemia and some tumors....need to recognize issues
Do individuals with Trisomy 21 Age Sooner?

- Years ago this was true, but with an active lifestyle including exercise, maintaining a reasonable weight, and being productive: aging is only slightly increased.
- MRI studies show plaques of Alzheimers but the incidence of symptoms is less than predicted.
Adults with Trisomy 21

- Longevity....70 and greater becoming more common

- Antioxidants.....Vitamin E 400 IU, Beta Carotene 200 mgm, and Vitamin C 500 mgm appear to improve health. Fresh fruits and vegetables, fish, and lower fat intake lowers cholesterol, helps maintain ideal weight, and lessens the risk of Diabetes
Things to Remember:

- Every individual with Trisomy 21 is unique....they are also the product of their family’s genes, education, and parenting.
- We all experience frustration but we respond to support....no different for anyone with Special Needs.
- Socialization, rules, expectations, motivation, and praise are the cornerstones of any successful person.
Questions....

☐ Thanks......Bruce