



# DOWN SYNDROME & PHYSICAL THERAPY

KERRY HAUGH, PT, DPT

BOARD CERTIFIED PEDIATRIC CLINICAL SPECIALIST

INSTITUTE ON DEVELOPMENT AND DISABILITY

OREGON HEALTH AND SCIENCE UNIVERSITY

HAUGHKE@OHSU.EDU



# OUTLINE OF PRESENTATION

- ROLE OF PHYSICAL THERAPY
- MUSCULOSKELETAL DIFFERENCES IN DOWN SYNDROME
- ORTHOPEDIC CONDITIONS
- GROSS MOTOR DEVELOPMENT
- IMPORTANCE OF PHYSICAL ACTIVITY
- IDEAS TO PROMOTE MOVEMENT AND STRENGTH

# PHYSICAL THERAPY

- The focus of physical therapy is to develop a body that is fit and functional for a lifetime
- *People who have Down syndrome can expect to live into their 60s, and they will need bodies that allow them to be active for that lifespan. As physical therapists, we help each child develop the body they will need as an adolescent and then as an adult*



# GOALS OF PHYSICAL THERAPY

- *Build muscle strength and balance*
- *Help create optimal posture*
- *Refine walking patterns*
- *Minimize risk for pain, orthopedic problems, obesity*
- *Encourage participation in physical activity*
- *Teach gross motor skills such as rolling, sitting, crawling, walking, running, jumping, riding tricycles, and stair climbing*

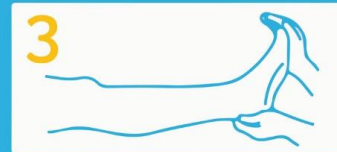
# MUSCULOSKELETAL FACTORS

- LOW MUSCLE TONE (HYPOTONIA)
  - limited resistance to passive movement of a muscle
  - affects all areas of the body, including oral motor skills and intestinal motility
- DECREASED COLLAGEN FIBERS
- DECREASED STRENGTH
- DELAYED SKELETAL MATURATION
- SHORT ARMS AND LEGS
- LIGAMENTOUS LAXITY (LOOSE LIGAMENTS)

# Beighton Scale

## Are You Hyperflexible?

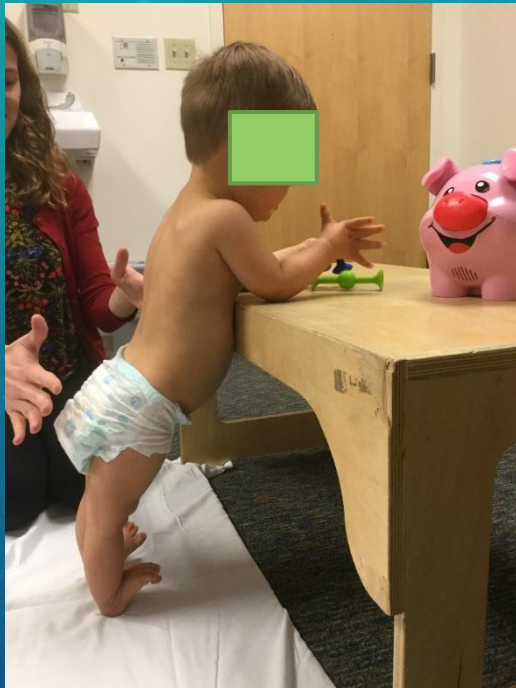
Give yourself 1 point for each of these 5 movements you can accomplish to determine your degree of hypermobility.



 DOCTOR ROWE

A positive Beighton score for adults is **5 out of the 9 possible points**; for children, a positive score is at least **6 out of 9 points**.

# HYPERFLEXIBILITY IN ACTION



# ORTHOPEDIC ISSUES: FEET

Calcaneal Eversion



Sandal gap





# ORTHOPEDIC ISSUES: FEET

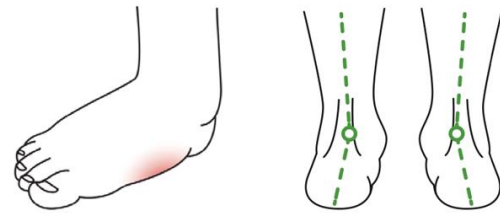
Hallux valgus



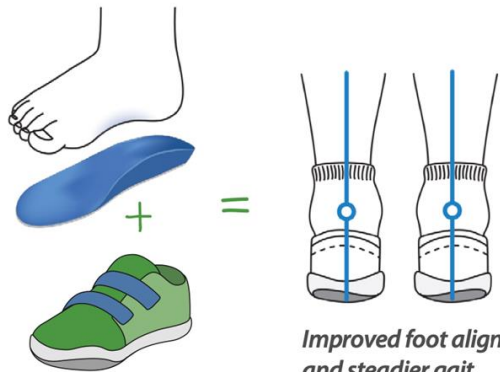
Pes planus, navicular drop



# ORTHOPEDIC ISSUES: FEET



*Moderate pronation, unstable foot position.*



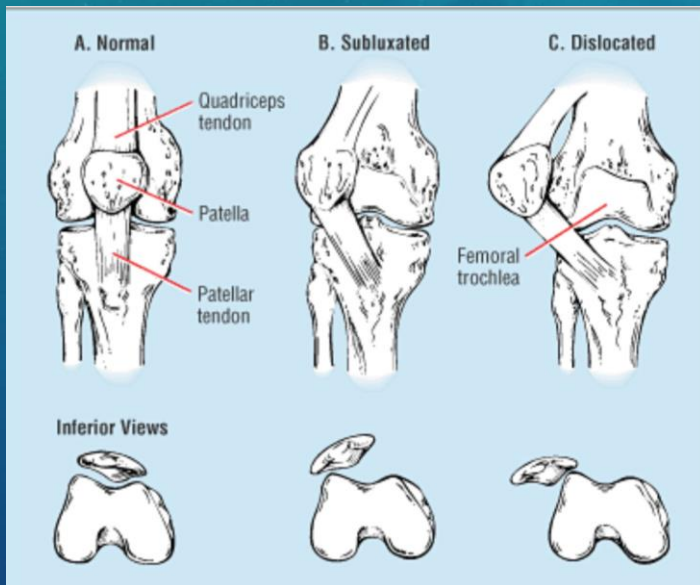
*Improved foot alignment and steadier gait.*



# ORTHOPEDIC CONDITIONS: KNEES

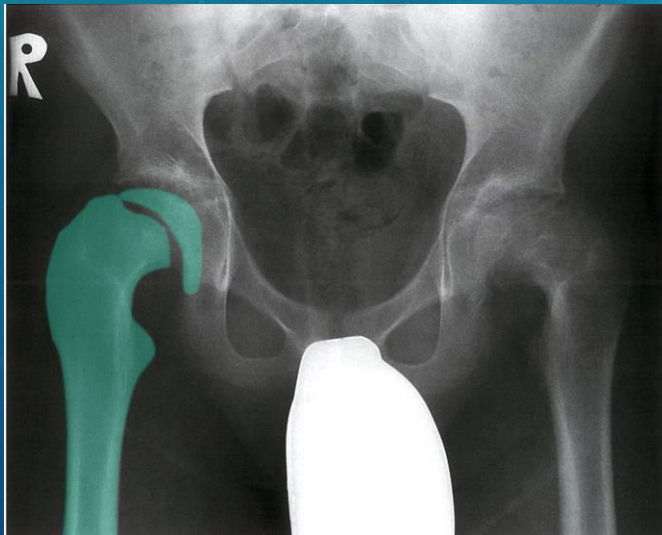
## Patellofemoral Instability (10-20%)

- Most patients had no pain with full ROM and no walking limitations, but arthritis and deformity resulting in disability may occur over time.
- Physical Therapy recommended (focus on quadriceps strengthening.) Try taping, knee sleeve, activity modifications
- Chronic dislocations may require surgery



# ORTHOPEDIC CONDITIONS: HIPS

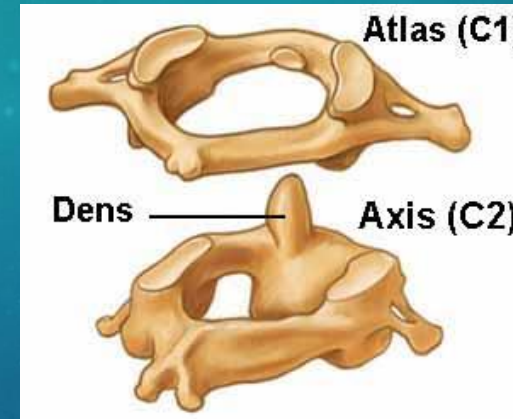
- Slipped Capital Femoral Epiphysis or SCFE (1.3%)
  - More common in overweight children ages 11-16; boys > girls
  - Osteonecrosis is common
  - Signs may include **hip, thigh, and knee discomfort** , **refusal to bear weight, limp when walking**
  - Treatment is surgical



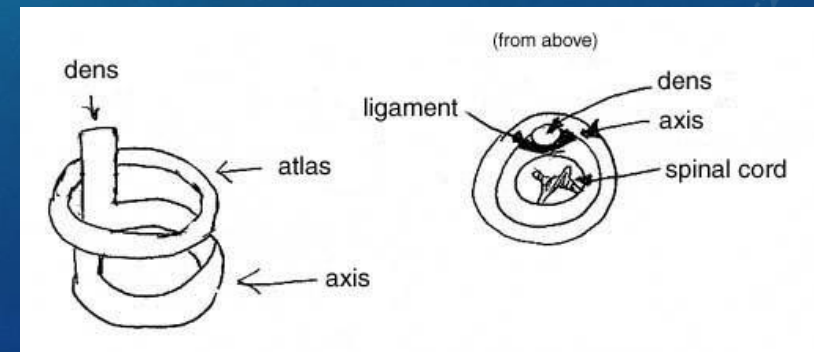
# ORTHOPEDIC CONDITIONS: SPINE

## Atlantoaxial Instability

- **excessive movement at the junction between the atlas (C1) and axis (C2) as a result of either a bony or ligamentous abnormality.**
- 20% of patients with DS have atlantoaxial instability
- 1-2% (of the 20%) are symptomatic and often require surgery
- Onset often at 5-15 yrs
- **Signs include neck pain, torticollis, changes in bowel or bladder control, hyperreflexia, clumsiness, and gait abnormalities.**

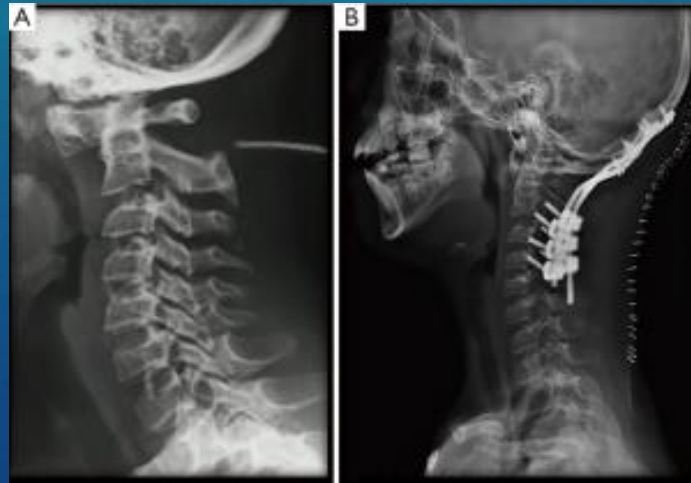


<https://www.spineuniverse.com/anatomy/vertebral-column>



# ORTHOPEDIC CONDITIONS: SPINE

- For children with DS who have these symptoms, lateral C-spine radiographs should be done
- Normal atlanto-dens interval < 3-5 mm
- If greater than 5 mm and symptomatic, treatment is surgical fusion of C1 and C2
- It is important for therapists working with kids with DS to monitor neurological status and cervical function. No somersaults or forceful flexion/extension!



<https://jss.amegroups.com/article/view/4409>

# GAIT CHARACTERISTICS IN DOWN SYNDROME

- Wide base of support
- Feet turned out
- Shorter step length
- Slower speed
- Increased lumbar lordosis
- Decreased push off
- Arms out for balance



# EARLY GROSS MOTOR DEVELOPMENT

Activity	Children with Down Syndrome		Typical Children	
	Average age	Range	Average age	Range
Holds head steady when sitting	5 months	3-5 months	3 months	1-4 months
Rolls over	8 months	4-12 months	5 months	2-10 months
Sits alone	9 months	6-16 months	7 months	5-9 months
Stands alone	18 months	12-38 months	11 months	9-16 months
Walks alone	23 months	13-48 months	12 months	9-17 months



# POST WALKING GROSS MOTOR DEVELOPMENT

ACTIVITY	CHILDREN WITH DS	TYPICAL CHILDREN
Steps up and off a single step	35 months	18-24 months
Jumps once	48 months	30 months
Alternates feet up stairs	57 months	36 months
Alternates feet down stairs	82 months	48 months
Rides a tricycle	57 months	36 months

# GROSS MOTOR ASSESSMENT

- GROSS MOTOR FUNCTION MEASURE (GMFM)
  - evaluates change that occurs over time
  - validated on children with Down syndrome and can plot scores on specific curves
  - Assesses skills up to the 5 year level (in typically developing children)
  - <https://canchild.ca/en/resources/44-gross-motor-function-measure-gmfm>

GROSS MOTOR FUNCTION MEASURE (GMFM)  
SCORE SHEET (GMFM-88 and GMFM-66 scoring)  
Version 1.0

Child's Name: \_\_\_\_\_ ID #: \_\_\_\_\_  
Assessment date: \_\_\_\_\_ GMFCS Level<sup>1</sup>  
Date of birth: \_\_\_\_\_ year / month / day  I  II  III  IV  V  
Chronological age: \_\_\_\_\_ year / month / day  
years/months Testing Conditions (eg. room, clothing, time, others present)  
Evaluator's Name: \_\_\_\_\_

The GMFM is a standardized observational instrument designed and validated to measure change in gross motor function over time in children with cerebral palsy. The scoring key is meant to be a general guideline. However, most of the items have specific descriptors for each score. It is imperative that the guidelines contained in the manual be used for scoring each item.

**SCORING KEY**

- 0 = does not initiate
- 1 = initiates
- 2 = partially completes
- 3 = completes
- NT = Not tested [used for the GMAE scoring]

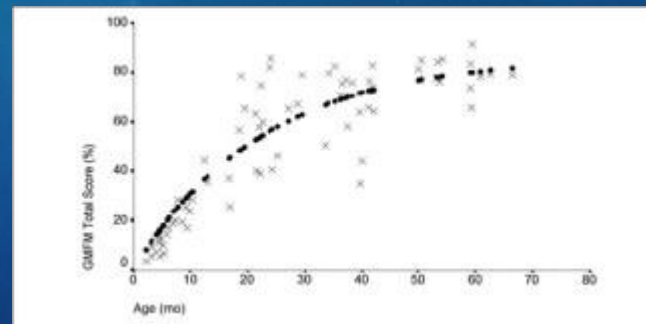
**It is now important to differentiate a true score of "0" (child does not initiate) from an item which is Not Tested (NT) if you are interested in using the GMFM-66 Ability Estimator Software.**

\*The GMFM-66 Gross Motor Ability Estimator (GMAE) software is available with the GMFM manual (2002). The advantage of the software is the conversion of the ordinal scale into an interval scale. This will allow for a more accurate estimate of the child's ability and provide a measure that is equally responsive to change across the spectrum of ability levels. Items that are used in the calculation of the GMFM-66 score are shaded and identified with an asterisk (\*). The GMFM-66 is only valid for use with children who have cerebral palsy.

**Contact for Research Group:**  
Dianne Russell, CanChild Centre for Childhood Disability Research, McMaster University, Institute for Applied Health Sciences, McMaster University, 1400 Main St. W., Rm. 408, Hamilton, L8S 1C7  
Tel: North America - 1 905 525-9140 Ext: 27550  
Tel: All other countries - 01 905 525-9140 Ext: 27850  
E-mail: [canchild@mcmaster.ca](mailto:canchild@mcmaster.ca) Fax: 1 905 522-0095  
Website: [www.fhs.mcmaster.ca/canchild](http://www.fhs.mcmaster.ca/canchild)

<sup>1</sup> GMFCS level is a rating of severity of motor function. Definitions are found in Appendix I of the GMFM manual (2002).

© Mac Keith Press, 2002 Page 1 GMFM SCORE SHEET



<https://canchild.ca/en/resources/44-gross-motor-function-measure-gmfm>

# PHYSICAL ACTIVITY HAS COGNITIVE BENEFIT!



Handwritten mathematical derivations for the derivative of a function. The top part shows the general formula for the slope of a secant line:  $\text{slope}(S) = \frac{y_1 - y_0}{x_1 - x_0} = \frac{g(x+h) - g(x)}{(x+h) - x} = \frac{g(x+h) - g(x)}{h}$ . Below this is a graph of a curve  $y = g(x)$  with a secant line and a tangent line at point  $(x, g(x))$ . The main part of the image shows the derivation of the derivative of  $f(x) = x^2$  using the limit definition:  $f'(x) = \lim_{h \rightarrow 0} \frac{f(x+h) - f(x)}{h} = \lim_{h \rightarrow 0} \frac{(x+h)^2 - x^2}{h} = \lim_{h \rightarrow 0} \frac{x^2 + 2xh + h^2 - x^2}{h} = \lim_{h \rightarrow 0} \frac{2xh + h^2}{h} = \lim_{h \rightarrow 0} (2x + h) = 2x$ . Other formulas shown include the power rule  $\frac{d}{dx}(x^n) = nx^{n-1}$  and the chain rule  $f'(a) = \lim_{h \rightarrow 0} \frac{f(a+h) - f(a)}{h}$ .



# EXERCISE CAPACITY

- Adults with DS have lower cardiovascular capacity with lower mean peak Oxygen consumption, minute ventilation and heart rate during exercise (Pitetti, 1992)

Contributing factors:

- o Lower lean body muscle mass
- o Lower muscle strength
- o Thyroid disorders
- o Hypotonia
- o Obesity
- o Impaired sympathetic response to exercise

Barnhard & Connolly, 2007

# NO LIMITS!



CHELSEA WERNER  
GYMNAST



JON SKOTLOSA  
WEIGHTLIFTER



ELI REIMER  
MOUNTAIN CLIMBER



KAREN GAFFNEY  
SWIMMER



LI XIANG  
GYMNAST



CHRIS NIKIC  
IRONMAN TRIATHLETE

# ACTIVITY IDEAS

## CORE STRENGTHENING (abdomen, back and pelvis area)

- Bridging



- Climbing (up the slide, rock wall)



- Crab Walk



- Therapy ball



- Superhero



# ACTIVITY IDEAS

## BALANCE

- Standing on one foot



- Standing on dynamic surface



- Walking on a line or balance beam



- Walking on targets



# ACTIVITY IDEAS

## FOOT STRENGTHENING



Using toes to pick up scarf or towel



Heel walking



Picking up small objects with toes



Toe walking



# ACTIVITY IDEAS

- TRICYCLE/BICYCLE RIDING
  - Great for muscle strengthening, coordination and balance
  - Children with Down syndrome are often more successful with straps on the pedals



<https://www.imperfectlyperfectlyf.com/post/diy-adaptive-bike-pedal-for-bicycle>



<https://coltenrobert.com/do-it-yourself-tutorials-for-special-needs-equipment/do-it-yourself-adaptive-pedals/>

THANK YOU!

QUESTIONS?

