Welcome Remarks from Connor Long

Advocate, Actor and Athlete

Friday, April 23, 2021 • 12:00pm – 1:00pm MT

Welcome to GLOBAL’s Spring Webinar! Thank you, Michelle and the Global Down syndrome Foundation for bringing us the Webinar Series.

My name is Connor Long, I’m from Colorado, and I lead a VERY active life!

I am an actor, an athlete and an advocate

I earned a black belt in Taekwondo & study ninja gym

I love cooking & eating gluten-free foods, especially pasta!

Introducing Today’s Speaker

❖ Today’s webinar is on Strength, Stability, Balance, and Endurance: Purposeful PT for Teens & Adults with Down Syndrome.

❖ Exercise is fun and being healthy helps you be able to try more fun things!

❖ And now I am pleased to introduce Sarah Mann!

Get Moving, Be Awesome!!!

Strength, Balance, Stability, Endurance PT for Teens and Adults with Down Syndrome

Dr. Sarah Mann, PT, DPT, MBA, NSCA-CPT

Physical Therapist Arvada, CO

Mann Method PT and Fitness, PLLC
**Objective For Today:**

- **WHY DOES PT MATTER FOR THIS AGE GROUP?**
  - UNIQUE PHYSIOLOGY: Understand the unique physical, sensory, mental, and motor characteristics of people with DS
  - MUSCULOSKELETAL: Hips, Knees, Spines
  - SENSORY SYSTEM: Eyes, Ears, and Joints
  - PHYSICAL THERAPY: Understand the role of physical therapy for adolescents and adults with DS, learn that PT should continue through the lifespan

- **WHAT CAN I DO TODAY TO GET STARTED?**
  - FOOTWEAR AND FOOT SUPPORT
  - MMPT EXERCISE PROGRAM: Lay out successful components of a sustainable and purposeful MMPT exercise program for adolescents/adults with DS
***Practical Take-Aways***

- Routine is key!
- Use a chart and schedule
- Assess foot support regularly
- Get started now!!!
Systems Review

Cardiovascular
- Cardiac history – PDA, VSD, ASD
- Pulmonary hypertension – 50% (NDSS 2015)
- Coronary artery disease
- Valve dysfunction

Neuromuscular
- Joint hypermobility
- Hypotonia

Endocrine
- Hypothyroid

Sleep
- Obstructive sleep apnea

Alzheimer’s
- Higher incidence of AD in our population

Neuromuscular System
- Posture
- Foot
- Hypotonia
- Ligamentous laxity
- Obesity
- Arthritis

Musculoskeletal Issues and Physical Fitness

<table>
<thead>
<tr>
<th>Musculoskeletal Issue</th>
<th>People with DS</th>
<th>General Population</th>
<th>Effect</th>
</tr>
</thead>
<tbody>
<tr>
<td>Scoliosis</td>
<td>~50%</td>
<td>3-5%</td>
<td>Decreased core strength, decreased scapular strength</td>
</tr>
<tr>
<td>Flat Feet</td>
<td>~91%</td>
<td>20-30%</td>
<td>Fatigue with walking/standing, knee pain, decreased motivation to move</td>
</tr>
<tr>
<td>Hypotonia</td>
<td>75-100%</td>
<td>4.6%</td>
<td>Resting muscle tone, commonly confused with inability to build strength</td>
</tr>
<tr>
<td>Obesity</td>
<td>Overweight: 37% Obese: 14%</td>
<td>Overweight: 25.5% Obese: 14%</td>
<td>Decreased energy, decreased motivation, decreased physical activity</td>
</tr>
<tr>
<td>Osteoarthritis</td>
<td>Unclear</td>
<td>~12%</td>
<td>Pain with movement</td>
</tr>
</tbody>
</table>

Medical Issues Affect Physical Performance

<table>
<thead>
<tr>
<th>Medical Issue</th>
<th>People with DS</th>
<th>General Population</th>
<th>Effect</th>
</tr>
</thead>
<tbody>
<tr>
<td>Heart issues</td>
<td>46-57%</td>
<td>2-3%</td>
<td>Lower cardiovascular capacity, fatigue</td>
</tr>
<tr>
<td>Sleep apnea</td>
<td>50-75%</td>
<td>3-7%</td>
<td>Fatigue, weight gain, poor focus</td>
</tr>
<tr>
<td>Hypothyroid</td>
<td>40%</td>
<td>4.6%</td>
<td>Decreased energy, fatigue, decreased motivation, weight gain</td>
</tr>
<tr>
<td>Obesity</td>
<td>Overweight: 37% Obese: 13%</td>
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<td>Decreased energy, decreased motivation, decreased physical activity</td>
</tr>
</tbody>
</table>
**Musculoskeletal and Cardiovascular**

<table>
<thead>
<tr>
<th>Primary Concern</th>
<th>People with DS</th>
<th>General Population</th>
</tr>
</thead>
<tbody>
<tr>
<td>Atlantoaxial instability</td>
<td>10-27% of population; 1-2% symptomatic</td>
<td>Rare — idiopathic or injury; 11% in population with RA</td>
</tr>
<tr>
<td>Hip instability</td>
<td>5-8%</td>
<td>1-3% of babies</td>
</tr>
<tr>
<td>Knee (Patellar) instability</td>
<td>5-9%</td>
<td>Less than 3%, usually associated with sports or trauma</td>
</tr>
<tr>
<td>Foot shape differences (Likely Underestimated)</td>
<td>91% - flat feet</td>
<td>86% - flat feet</td>
</tr>
<tr>
<td>Hip replacement</td>
<td>52% - foot pain</td>
<td>55% - hallux valgus</td>
</tr>
<tr>
<td>Heart Rate (lower heart rate, lower max heart rate)</td>
<td>179 - (0.56*age)</td>
<td>220 - age</td>
</tr>
</tbody>
</table>

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**Spine, Hips, and Knees**

In our practice – increased incidence of:
- Hip dislocation
- Hip dysplasia
- Hip replacement
- Hip PAO surgery
- Hip impingement
- Knee patellar dislocation
- Scoliosis
- Foot pain

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**Common Sensory Integration Impairments**

- **Visual**
  - Increased incidence of visual impairment – greater than 50% of people with DS
  - Increased incidence of nystagmus and strabismus
- **Hearing/Vestibular**
  - Increased incidence of hearing impairment – greater than 50% of people with DS
  - Impact to cranial nerve VIII (vestibulocochlear) makes concurrent involvement with vestibular function likely
  - Documented differences of inner ear anatomy/shape may impact vestibular function
- **Proprioception**
  - Decreased feedback from proprioceptive sensors in joints with ligamentous laxity

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Sarah’s recommendations:
- Hip x-rays
- Scoliosis x-rays
- Foot support
- Good shoes
- Regular vision check
- Regular hearing check
Strengths in Learning Style

People with DS:
- Great visual learners – VISUAL CHART
  – TEACCH Program out of UNC Chapel Hill
- Great imitators
- Great adherence to routine
- Supportive and knowledgeable supervision
- Accountability, motivation and direction

Dr. Lina Patel, PsyD
Dr. Dennis McGuire, PhD

***DO THE ROUTINE!!!***

- Great visual learners
  – Excellent with visual charts and schedules
- Great adherence to routine
  – Allows for experience and mastery of exercises
  – Add one small thing at a time, and practice many, many reps
- Don’t stop the routine 😊

Why Is PT Important for My Teen or Adult with DS?

PHYSICAL THERAPY: What is the role of PT in the life of a teen or adult with DS?

- Set up for success
- Knowledge of unique physiology
- Building a purposeful program
- Targeted exercise for maximal effect

Role of Physical Therapy for Adolescents/Adults with Down Syndrome

- People with DS are living longer lives
- Aging process accelerated
- Specific physiology
- Learning styles
- Need successful strategies
- Rehab from surgery
- Stay active and healthy to participate

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Pat Winders’ Principles of PT

“Physical therapy is a critical service, not because it will accelerate a child's rate of development, but because it will improve a child's long-term functional outcome” - PW

- Long term functional outcome
- Understand and minimize compensatory movement patterns of people with DS
- Strategically build strength in key muscle groups
- Focus on gait, posture, and exercise

***Why these movements?***

- Based on studying hundreds of individuals and their compensation patterns
- Foundational movements
  - Abdominal strengthening
  - Gluteal strengthening
- Hip stability
- Vestibular/Balance components
- Big movements, simple cueing
- No equipment

***Mann Method™ PT Principles***

- **Foundational Exercises**: multi-joint movements that target abdominal activation, gluteal activation, hip stabilization, neuromuscular sequencing
- **Hip Strengthening Exercises**: specific exercises that target gluteal and lateral hip musculature to improve hip strength and stability
- **Vestibular Exercise**: balance and coordination exercises that target the visual-vestibular system and integrate stabilization challenges
- **Endurance**: sequencing exercises and progressions that enhance cardiovascular endurance over the course of the session

Foundational Exercises: multi-joint movements that target abdominal activation, gluteal activation, neuromuscular sequencing

- Squats
- Planks
- Push-ups
- Gluteal Bridges

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Hip Strengthening Exercises: specific exercises that target gluteal and lateral hip musculature to improve hip strength and stability.

Transfer Patterns

Marches

Quadruped Series

Kneeling Series

Endurance

What is our goal heart rate?

Using your calculated maximal heart rate, you can calculate your own zones:

Maximal heart rate = 220 - (0.56 x age)

If you are 30 years old and have DS:

Max HR = 179 - (0.56 x 30) = 162

50% = 0.5 x 162 = 81
70% = 0.7 x 162 = 113
90% = 0.9 x 162 = 146

Compared to 30 yrs old without DS:

Max HR = 220 - 30 = 190

50% = 0.5 x 190 = 95
70% = 0.7 x 190 = 133
90% = 0.9 x 190 = 171

Hilgenkamp 2021 – used with permission

What can I do to get started today?

The 3 F's!

FOOTWEAR

FOOT SUPPORT

FITNESS: specific, routine-based, visual
Exercise Recommendations

- **Key to success:** Establishing a predictable routine - same order, same place, same time
- Many athletes enjoy leading/teaching/coaching the exercises
- Adolescents over 12 years old can begin weight training with supervision (Consistent with ACSM recommendations for strength training)

The Flat Foot

- Orthotic support options – full length arch support
- Superfeet
- Sole insoles
- Custom insoles – Medicaid covers this!
- Cascade DAFO inserts
- KidSoles for young teens

***Get Good Shoes – TODAY!***

- Brooks Adrenaline (adult size 5.5 ladies and up)
- Saucony Excursion (kids size 10.5-3)
- Saucony Triumph/Cohesion (adult, wider foot)
- Brooks Beast (adult wider foot, heavier pronator)
- Benefits of good shoes – improves foot position
  - Decreases propensity for hallux valgus, great toe abduction
  - Improves foot, knee, hip position
  - Improves foot comfort
  - Improves participation in activity

***Always consult your physician before beginning an exercise program***

<table>
<thead>
<tr>
<th>What to do</th>
<th>What it looks like</th>
<th>Why it helps</th>
</tr>
</thead>
<tbody>
<tr>
<td>10 Squats</td>
<td><img src="image1.png" alt="Image" /></td>
<td>Big muscle movement, hip stability, leg strength, hip strength, core strength</td>
</tr>
<tr>
<td>10 Side to Side Tilts</td>
<td><img src="image2.png" alt="Image" /></td>
<td>Visual vestibular coordination, lateral hip strength, rhythmic balance reset</td>
</tr>
<tr>
<td>10 Over Under Passes</td>
<td><img src="image3.png" alt="Image" /></td>
<td>Visual vestibular coordination, increased vestibular proprioception</td>
</tr>
<tr>
<td>10 Bridges</td>
<td><img src="image4.png" alt="Image" /></td>
<td>Hip strength, increased proprioception, core stability</td>
</tr>
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</table>
**15 Squats**
15 repetitions up and down — easiest to begin with hand support, 15 inch ball to tap to

**10 push-ups**
(knees or toes)
10 repetitions
Hands by chest
Knees bent
Knees together
Push-up
Control down

**20 second plank**
(elbows or hands)
10-20 seconds
Feet together
Toes pointing down
Eyes up

**10 Bridges**
10 times with 5 second hold at the top, slow and controlled

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**What Can I do Now?**
- Get good shoes!
- Work with a PT — in-person and telehealth options!
- Participate in a research study for exercise — UNLV - thessa.hilgenkamp@unlv.edu
- GiGiFIT – local playhouse and GiGi’s At Home online – free
- Get Moving, Be Awesome!

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QUESTIONS?

Community Resources

Community programs for individuals with Down syndrome:

- Mann Method Physical Therapy and Fitness PLLC
  - www.mannmethodpt.com
  - Contact Sarah Mann: sarah@mannmethodpt.com
  - Call: 720-702-8093
- Global Down Syndrome Foundation
  - www.gdsf.org
  - Call: 303-707-2725
  - Email: info@globaldownsyndrome.org
- Six Center for Down Syndrome
  - Contact: 303-707-2725
- Rocky Mountain Down Syndrome Association (RMDSA)
  - www.rmdsa.org
  - Call: 303-707-2725
- GISF’s Playhouse Denver
  - www.gisfplayhousedenver.org
  - DenverPlayhouse.org
- Highlands Ranch Therapeutic Recreation
  - http://www.hrcaonline.org/Recreation/TherapeuticRecreation
  - Summer Aiken: 303-471-7043 or summer.aiken@hrcaonline.org

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