GLOBAL
DOWN SYNDROME FOUNDATION

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

Welcome Remarks from Connor Long
Advocate, Actor and Athlete

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

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Welcome!

- 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!

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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!

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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

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Dr. Sarah Mann, PT, DPT

BA 1999

MBA 2002

DPT (Doctor of Physical Therapy) 2012

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Dr. Jennifer Spiric, PT, DPT

BA Integrative Physiology 2008

DPT (Doctor of Physical Therapy) 2012

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Jamie McGrew MOTR/L

BA Psychology 1998

Master of Occupational Therapy 2000

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Dr. Stephanie Hansen, PT, DPT

BA 2005

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JJ Olson

BA International Relations & Spanish 2006

Master of Arts, Government 2012

Mann Method™ PT and Fitness PLLC 2020

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Dr. Thessa Hilgenkamp, PhD

- University of Nevada, Las Vegas
  - CArdiovascular Research and Exercise (CARE) Lab
- 13 years of research with individuals with ID and with DS
- Loves to run and dance

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Sarah Mann Affiliations/Disclosures

Consultant

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Objectives 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

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Practical Take-Aways

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

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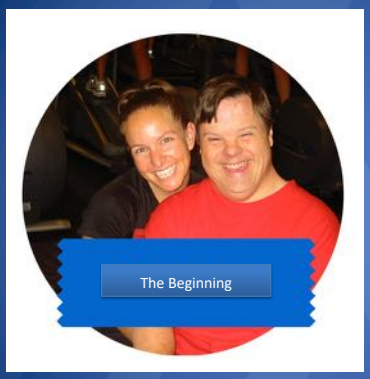

- Working with adolescents and adults with DS as fitness trainer since 2004
- Mentored by Pat Winders at the Sie Center
- Adolescent Sports Medicine PT at Sie Center 2012-2015
- Worked directly with over 750 unique individuals with DS to develop these PT-based exercise recommendations

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

UNIQUE PHYSIOLOGY: Understand the unique physical, mental, and motor characteristics of people with Down syndrome

- Flexible ligaments
- Flexible joints
- Lower resting muscle tone
- Flat feet
- Visual learners
- Processing time

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Common Medical Issues

MEDICAL FOLLOW-UP AND MILESTONES:

1. Yearly physicals/well-check-ups (every 1-2 years)
2. Key points for follow-up care:
   - Attention to growth and development
   - Obesity can be contributing factor to obstructive sleep apnea
   - Annual hearing testing
   - Annual eye examination
   - Annual thyroid screening
   - Celiac testing
   - Attention to skin issues (dry, folliculitis, eczema, alopecia)
   - Sleep history with attention to OSA symptoms
   - History of sexual development, menarche and management of fertility/contraception
   - Guardianship discussion and transition planning begins age 14-15

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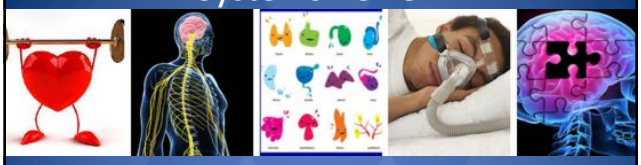
Systems Review



Cardiovascular
- Cardiac history – PDA.VSD, ASD
  - 50% (NDSS 2015)
- Pulmonary hypertension
  - 37.5% (Mourato 2014)
  - 90% if CHD and DS vs 40% CHD without DS (King 2011)
- Coronary artery disease
- Valve dysfunction
  - 46-57% (Smith 2001, Roizen 2003)

Neuromuscular
- Joint hypermobility
  - 100%
- Hypotonia
  - 100%
- Ligamentous laxity
  - 88% (Bennet 1982)
- Seizures
  - 1-13% (Bull 2011)
- Depression
  - 30% (Barnhart 2007)

Endocrine
- Hypothyroid
  - 40% prevalence by adulthood (Barnhart 2007)

Sleep
- Obstructive sleep apnea
  - 50-75% (Bull 2011)
  - DSMIG 2018 ~80.4% (Heubi 2017)

Alzheimer's
- Higher incidence of AD in our population
- Studies on exercise helping people with AD

Mourato 2014, King 2011, Smith 2001, Roizen 2003, Bennet 1982, Bull 2011, Bull 2020, Barnhart 2007, Bittles 2007, Lancet 2014, NDSS 2015

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Medical Issues Affect Physical Performance

Medical Issue	People with DS	General Population	Effect
Heart issues – mitral valve prolapse (Barnhart 2007, Finesilver 2002, Smith 2001, Roizen 2003, Delling 2014)	46-57%	2-3%	Lower cardiovascular capacity, fatigue
Sleep apnea (Bull 2011, Bull 2020, Punjabi 2008)	50-75%	3-7%	Fatigue, weight gain, poor focus
Hypothyroid (Barnhart 2007, Golden 2009)	40%	4.6%	Decreased energy, fatigue, decreased motivation, weight gain
Obesity (Real de Asua 2014)	Overweight: 37% Obese: 37%	Overweight: 25.5% Obese:14%	Decreased energy, decreased motivation, decreased physical activity

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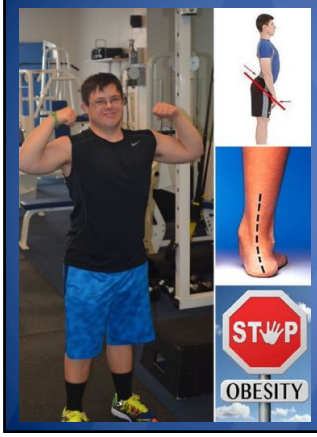
Musculoskeletal System



- Posture
  - Scoliosis (up to 50% in population with DS), anterior pelvic tilt
- Foot
  - Flat, orthotic supports
  - Foot pain
- Hypotonia
  - Muscle tone
- Ligamentous Laxity
  - Increased flexibility
  - Hip, knee, foot pain
  - Joint wear and tear?
- Obesity
  - Exercise, diet
- Arthritis

Wheeless 2015, Mendez 1988, Hresko 1993, Mahy 2010, Barnhart 2007

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Musculoskeletal Issues and Physical Fitness

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

Wheeless 2015, Mendez 1988, Hresko 1993, Mahy 2010, Barnhart 2007, Real de Asua 2014, Foley 2019

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Musculoskeletal and Cardiovascular

Primary Concern	People with DS	General Population
Atlantoaxial instability	10-27% of population, 1-2% symptomatic	Rare – idiopathic or injury 11% in population with RA
Hip instability -Likely Underestimated	5-8%	1-3% of babies
Knee (Patellar) Instability	5-9%	Less than 1%, usually associated with sports or trauma
Foot shape differences - Likely Underestimated	91% - flat feet 62% - foot pain 55% - hallux valgus 15% - metatarsal adductus	26% - flat feet 17-30% - foot pain 23-36% - hallux valgus
Heart Rate – lower heart rate, lower max heart rate	179 - (0.56*age)	220-age

Bull 2011, Bull 2020, Bennet 1982, Fernhall 2001 http://www.hipdysplasia.org/, Fithian 2004, Foley 2019, Perotti 2018, Hendry 2018, Pita-Fernandez 2018, Hilgenkamp 2021

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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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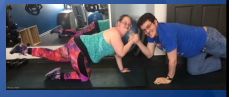
Spine, Hips, and Knees

Sarah's recommendations:

- Hip x-rays
- Scoliosis x-rays
- Foot support
- Good shoes
- Regular vision check
- Regular hearing check





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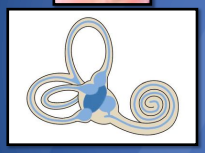
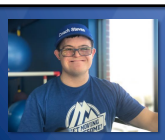
Common Sensory Integration Impairments

- 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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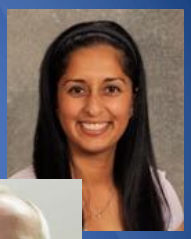
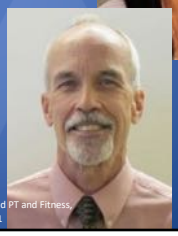
Strengths in Learning Style

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

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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 ☺

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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

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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

Brown 2001, NDSS 2015

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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

Photo – Winders 2014 Gross Motor Skills for Children with Down Syndrome

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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

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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

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

Squats

Planks

Push-ups

Gluteal Bridges

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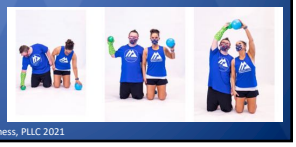
Hip Strengthening Exercises: specific exercises that target gluteal and lateral hip musculature to improve hip strength and stability

Transfer Patterns

Marches

Quadruped Series

Kneeling Series



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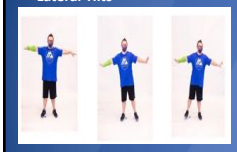
Vestibular and Balance Exercises:

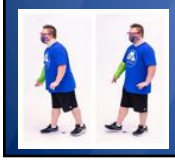
Balance/coordination exercises targeting the visual-vestibular system and integrating stabilization challenges

Lateral Tilts

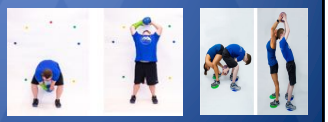


Rotational Ball Passes Around

Anterior/Posterior Tilts



Over-Under Passes



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Endurance
What is our goal heart rate?

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

Maximal heart rate: 179-(0.56*age)

If you are **30 years old and have DS**:
Max HR = 179- (0.56*30) = 162

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

Compared to **30 yrs old without DS**:
Max HR = 220-30 = 190

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

Hilgenkamp 2021 – used with permission

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What can I do to get started today?

The 3 F's!

FOOTWEAR

FOOT SUPPORT

FITNESS: specific, routine-based, visual

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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)

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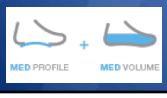
The Flat Foot



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

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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**

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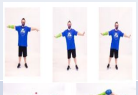
Mann Method™ PT

Beginning Exercise Options

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

What to do	What it looks like	Why it helps
10 Squats		Big muscle movement, hip stability, leg strength, hip strength, core strength
10 Side to Side Tilts		Visual vestibular coordination, lateral hip strength, rhythmic balance reset
10 Over Under Passes		Visual vestibular coordination, increased vestibular proprioception
10 Bridges		Hip strength, increased proprioception, core stability

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Mann Method™ PT
Foundational Exercise Options
*** Always consult your physician before beginning an exercise program ***

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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PT-Based Fitness for Individuals with Ds

Overall Goals:

- Joint Stability
- Strength
- Endurance
- Balance/Coordination
- Successful
- Home and Community practice

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

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QUESTIONS?

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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: 720-524-4659
- **Global Down Syndrome Foundation**
  - www.globaldownsyndrome.org
  - 303-321-6277
  - Email - info@globaldownsyndrome.org
- **Sie Center for Down Syndrome**
  - Contact: 720-777-6750
- **Rocky Mountain Down Syndrome Association (RMDSA)**
  - www.rmdsa.org
  - Call: 303.797.1699
- **GiGi's Playhouse Denver**
  - www.gigisplayhouse.org/denver
  - Denver@gigisplayhouse.org
- **Highlands Ranch Therapeutic Recreation**
  - http://hrcaonline.org/Recreation/TherapeuticRecreation
  - Summer Aden: 303-471-7043 or summeraden@hrcaonline.org

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