Welcome to Get Moving, Be Awesome! – Physical Therapy & Fitness for Adolescents & Adults with Down Syndrome!

Global Down Syndrome Foundation’s Webinar Series

Presenters: Michelle Sie Whitten, President & CEO & Dr. Sarah Mann, PT, DPT, MBA, NSCA-CPT

Tuesday, December 5\textsuperscript{th}, 2017
Global Down Syndrome Foundation
A Unique Affiliate Model!

The Global Down Syndrome Foundation is part of a network of affiliate organizations that work closely together on a daily basis to deliver on our mission, vision, values, and goals:

**Global & Affiliates**

- **Global**: was established as a 501(c)3 in 2009 and is “Dedicated to significantly improving the lives of people with Down syndrome through Research, Medical Care, Education, and Advocacy”

- **Affiliates are:**
  - Established with a lead gift from Anna & John J. Sie Foundation
  - Must work closely together to benefit people with Down syndrome
  - Must be self-sustaining financially
Get Moving, Be Awesome!!!
Physical Therapy for Adolescents and Adults with Down Syndrome

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

Mann Method
PT and Fitness, PLLC
Professional Background

Education

- Boulder, BA 1999
- DU, MBA 2002
- School of Medicine, DPT (Doctor of Physical Therapy) 2012

Professional Experience

- NSCA National Strength and Conditioning Association
- Children’s Hospital Colorado, Anna and John J. Sie Center for Down Syndrome
- Mann Method PT and Fitness PLLC
• Working with adolescents and adults with DS as fitness trainer since 2004
• Directly mentored by Pat Winders at the Sie Center
• Adolescent Sports Medicine PT at Sie Center 2013-2015
• Worked directly with over 300 unique individuals with DS to develop these PT-based exercise recommendations
Objectives For Today:

- WHY DOES PT MATTER FOR THIS AGE GROUP?
  - UNIQUE PHYSIOLOGY
  - PHYSICAL THERAPY
  - RESEARCH
- WHAT CAN I DO TODAY TO GET STARTED?
  - FOOTWEAR AND FOOT SUPPORT
  - EXERCISE PROGRAM
Practical Take-Aways

Establish a predictable routine

Assess foot support regularly

Use a visual chart or schedule

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

UNIQUE PHYSIOLOGY
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
Common Medical Issues

MEDICAL FOLLOW-UP AND MILESTONES:
1. Yearly physicals/well-check-ups (every 1-2 years)
2. Key points to 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
# Systems Review – Aging with DS

<table>
<thead>
<tr>
<th>Cardiovascular</th>
<th>Neuromuscular</th>
<th>Endocrine</th>
<th>Sleep</th>
<th>Alzheimer’s</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Cardiac history</td>
<td>• Joints</td>
<td>• Thyroid function</td>
<td>• Obstructive sleep apnea</td>
<td>• Higher incidence of AD in our population</td>
</tr>
<tr>
<td></td>
<td>• Muscle tone</td>
<td></td>
<td>• 50-75% (Bull 2011)</td>
<td>• Studies on exercise helping people with AD</td>
</tr>
<tr>
<td></td>
<td>• Seizures</td>
<td></td>
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Systems Review – Musculoskeletal

• Posture
  – Scoliosis (up to 50% in population with DS), anterior pelvic tilt

• Foot
  – Flat, orthotic supports

• Hypotonia
  – Muscle tone

• Ligamentous Laxity
  – Increased flexibility

• Obesity
  – Exercise, diet

• Arthritis


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System Review –
Strengths in Learning Style

People with DS:
• Great visual learners
• Great imitators
• Great adherence to routine
• Supervision, support, accountability, motivation, and direction
• Hard-working physical therapy patients, lifelong fitness participants

Dr. Lina Patel, PsyD
Dr. Dennis McGuire, PhD
Why Is PT Important for My Teen or Adult with DS?

PHYSICAL THERAPY
Role of Physical Therapy for Adolescents/Adults with Down Syndrome

Brown 2001, NDSS 2015

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Physical Therapy for Adolescents and Adults with DS: Why Does It Matter for People with Down syndrome?

- Metabolic Rate?
- Obesity?
- Sedentary lifestyle?
- Recommended amount of physical activity?
- Joint wear and tear?

When you implement PT-based physical activity recommendations for people with DS, lives change

- Improve Muscle Strength
- Decrease body weight
- Improve functional ability

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

RESEARCH
Current Exercise Research
Cardiovascular and Strength
Current Exercise Research – Cissik 2012

• Strength training for people with DS?
• Cardiovascular training for people with DS?
• What is best?
Current Exercise Research
Help People Move Better
What can I do to get started today?

The 3 Fs:

FOOTWEAR

FOOT SUPPORT

FITNESS
Systems Review – Musculoskeletal

- **Posture**
  - Scoliosis (up to 50% in population with DS), anterior pelvic tilt

- **Foot**
  - Flat, orthotic supports

- **Hypotonia**
  - Muscle tone

- **Ligamentous Laxity**
  - Increased flexibility

- **Obesity**
  - Exercise, diet

- **Arthritis**

The Flat Foot

- Orthotic support options – full length arch support
- Superfeets
- Sole Insoles
- Custom insoles – Medicaid covers this!
- Vasyli inserts
- Cascade dafo inserts
Get Good Shoes – TODAY!

- Brooks Adrenaline (adult size 5.5 ladies and up)
- Saucony Excursion (kids size 10.5-3)
- Saucony Triumph (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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Start an Active Routine – TODAY!

- Great visual learners
  - Excellent with visual charts and schedules
- Great adherence to routine
  - Allows for experience and mastery of exercises
- Start with one small change!

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Is this exercise dangerous for adolescents and adults with DS?

• What about the neck, hips, knees and heart?
  – Atlantoaxial instability
  – Hip instability
  – Knee instability
  – Heart issues

• Exercise should be supervised to start

# Necks, Hips, Knees, and Hearts

<table>
<thead>
<tr>
<th>Primary Concern</th>
<th>People with DS</th>
<th>General Population</th>
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<tbody>
<tr>
<td>Atlantoaxial instability</td>
<td>15% 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 1%, usually associated with sports or trauma</td>
</tr>
<tr>
<td>Congenital Heart issues</td>
<td>~50%</td>
<td>2-3%</td>
</tr>
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Exercise Recommendations

• Key to success: Establishing a predictable routine

• Many athletes enjoy leading/teaching/coaching the exercises

• Key to success: Establishing a predictable routine - same order, same place, same time

• Adolescents over 12 can begin weight training with supervision (Consistent with ACSM recommendations for strength training)

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<table>
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<tr>
<th>Exercise</th>
<th>Repetitions/Details</th>
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<tbody>
<tr>
<td><strong>15 Squats</strong></td>
<td>15 repetitions up and down – easiest to begin with hand support, 15 inch ball to tap to</td>
</tr>
<tr>
<td><strong>10 push-ups (knees or toes)</strong></td>
<td>10 repetitions Hands by chest Knees bent Knees together Push-up Control down</td>
</tr>
<tr>
<td><strong>20 second plank (elbows or hands)</strong></td>
<td>10-20 seconds Feet together Toes pointing down Eyes up</td>
</tr>
<tr>
<td><strong>10 Bridges</strong></td>
<td>10 times with 5 second hold at the top, slow and controlled</td>
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SUCCESSFUL BUSINESS IS DOING WHAT YOU LOVE SERVING PEOPLE WHO LOVE WHAT YOU DO.

#BeTheException

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QUESTIONS?
Community Resources

Community programs for individuals with Down syndrome:

- **Global Down Syndrome Foundation Health and Wellness Programs**
  - [www.globaldownsyndrome.org](http://www.globaldownsyndrome.org)
  - Chelsea Hedrick: Office 303.468.6673 [chedrick@globaldownsyndrome.org](mailto:chedrick@globaldownsyndrome.org)
- **Mann Method Physical Therapy and Fitness PLLC**
  - [www.mannmethodpt.com](http://www.mannmethodpt.com)
  - Contact Sarah Mann: [sarah@mannmethodpt.com](mailto:sarah@mannmethodpt.com)
  - Call: 720-524-4659
- **Sie Center for Down Syndrome**
  - Contact: 720-777-6750
- **Wheatridge Recreation Center Therapeutic Recreation**
  - [http://www.ci.wheatridge.co.us/567/Therapeutic-Recreation](http://www.ci.wheatridge.co.us/567/Therapeutic-Recreation)
  - Call 303-231-1300
- **Highlands Ranch Therapeutic Recreation**
  - [http://hrcaonline.org/Recreation/TherapeuticRecreation](http://hrcaonline.org/Recreation/TherapeuticRecreation)
  - Summer Aden: 303-471-7043 or [summer.aden@hrcaonline.org](mailto:summer.aden@hrcaonline.org)
- **Denver Recreation Centers**
  - Free Rec Center membership for children age 5-18
  - [https://www.denvergov.org/adaptive_recreation](https://www.denvergov.org/adaptive_recreation)
References


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