

# **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<sup>th</sup>, 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”

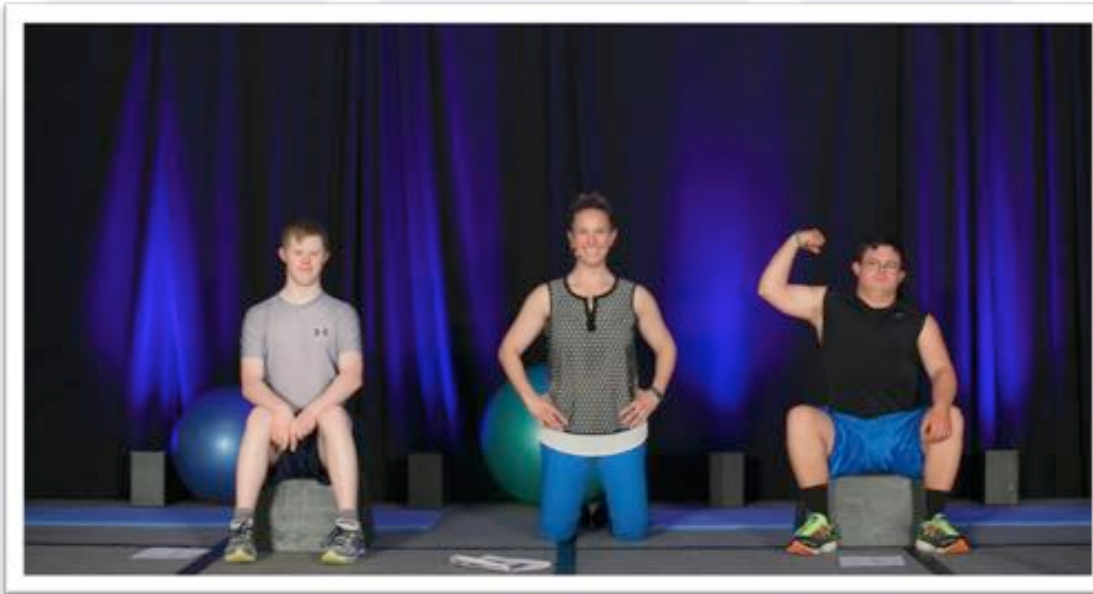
❖ **Affiliates are:**

- 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



BA 1999



MBA 2002



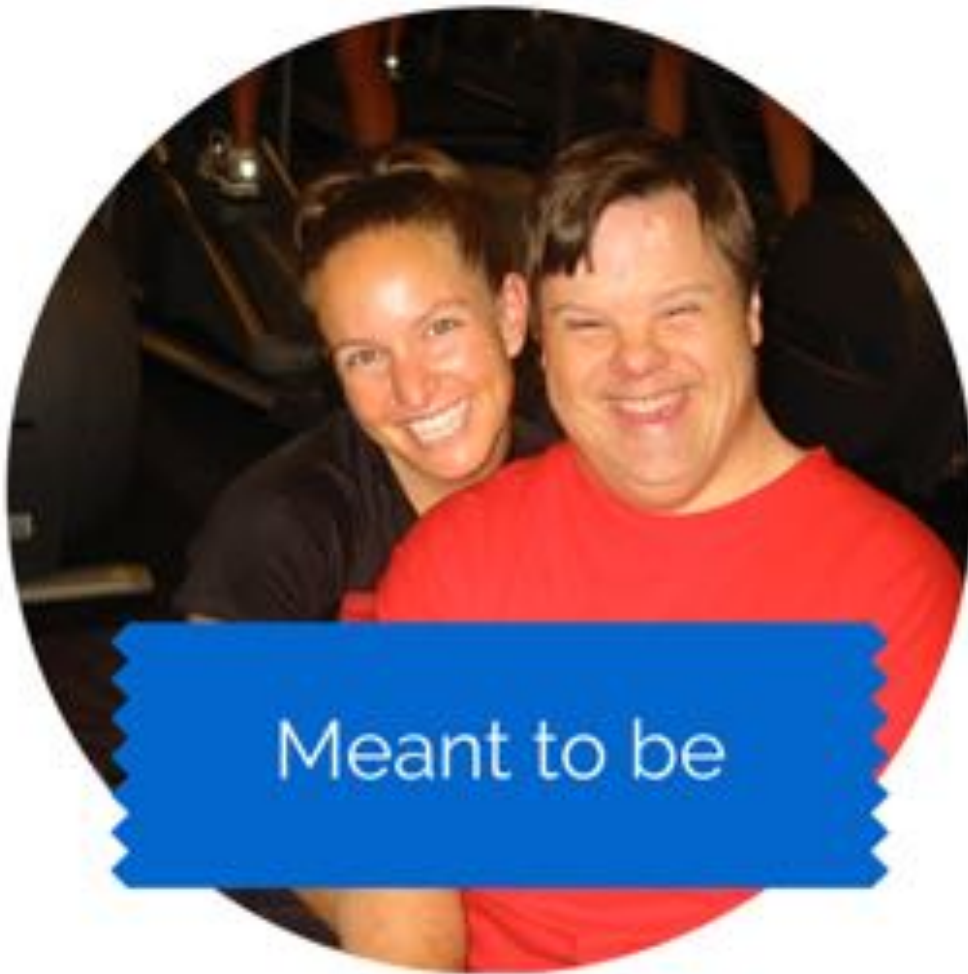
DPT (Doctor of Physical Therapy) 2012

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## Professional Experience



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

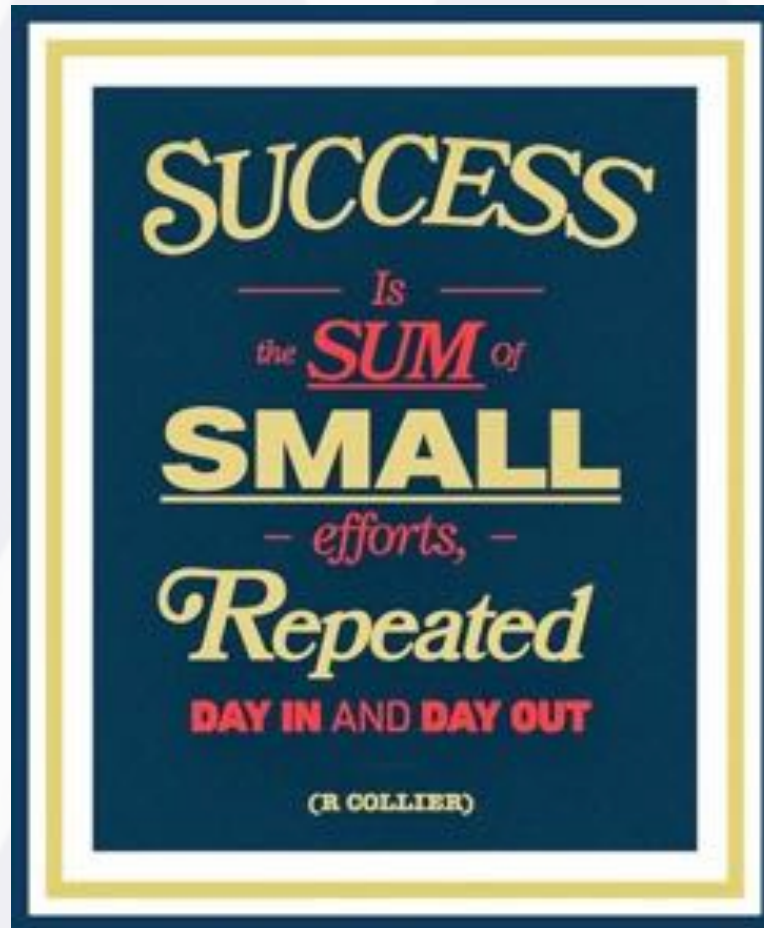
➤ EXERCISE PROGRAM



# 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



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- 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



## Cardiovascular

- Cardiac history

## Neuromuscular

- Joints
- Muscle tone
- Seizures

## Endocrine

- Thyroid function

## Sleep

- Obstructive sleep apnea
  - 50-75% (Bull 2011)

## 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, Barnhart 2007, Bittles 2007, Lancet 2014, NDSS 2015



# Systems Review – Musculoskeletal



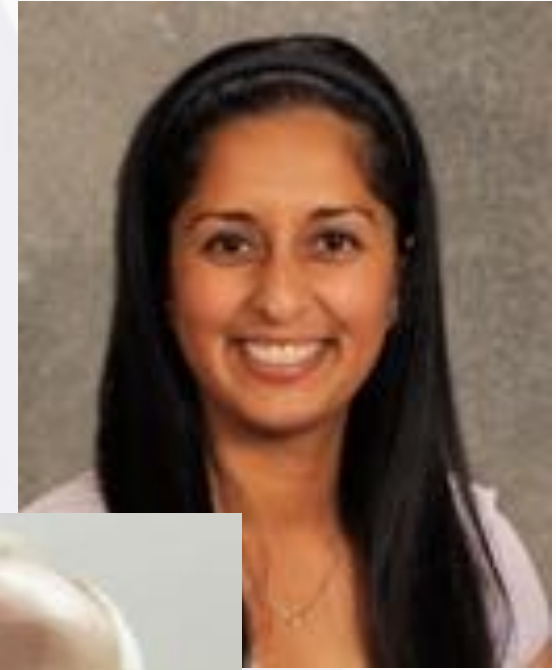
- Posture
  - Scoliosis (up to 50% in population with DS), anterior pelvic tilt
- Foot
  - Flat, orthotic supports
- Hypotonia
  - Muscle tone
- Ligamentous Laxity
  - Increased flexibility
- Obesity
  - Exercise, diet
- Arthritis

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

# 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



## 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?



Allison 1995, Barnhart 2007, Real de Asua 2014, Izquierdo-Gomez 2014,  
Andriolo 2010, Luke 1994, Wilmore 1999, Pitetti 1995, Mahy 2010, Draheim 2002

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# 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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Shields 2010, Shields 2008, Rimmer 2004, Tsimaras 2004, Kliegman 2011, NCPAD 2011

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

## RESEARCH



# Current Exercise Research

## Cardiovascular and Strength



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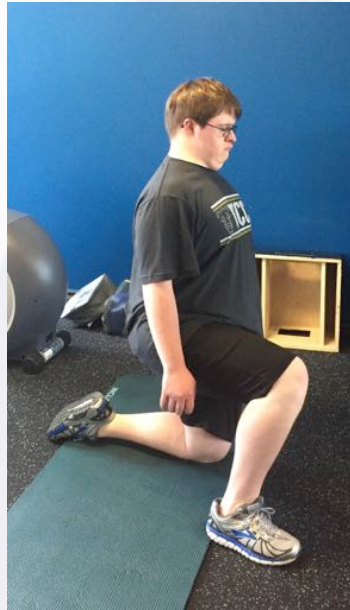
## Current Exercise Research – Cissik 2012

- 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
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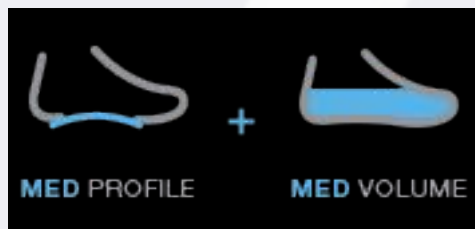
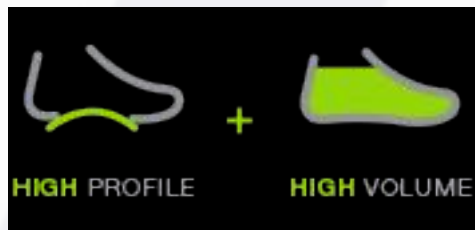


# The Flat Foot



## The Flat Foot

- Orthotic support options – full length arch support
- Superfeet
- 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**

# 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!

1



2



3



4



# 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

Primary Concern	People with DS	General Population
Atlantoaxial instability	15% of population, 1-2% symptomatic	Rare – idiopathic or injury 11% in population with RA
Hip instability	5-8%	1-3% of babies
Knee (Patellar) Instability	5-9%	Less than 1%, usually associated with sports or trauma
Congenital Heart issues	~50%	2-3%

Bull 2011, Bennet 1982, <http://www.hipdysplasia.org/>, Fithian 2004



# 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)



# Beginning Exercise Recommendations

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



# QUESTIONS?



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# 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>
  - Call 303-231-1300
- **Highlands Ranch Therapeutic Recreation**
  - <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>

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