Mass General Brigham

DSMIG 2026: International Summit for Fitness in Down Syndrome

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Disclosures

- ○ I treat patients with Down syndrome
- ○ I have been asked to serve as an expert witness for legal cases where Down syndrome is discussed
- ○ I serve in an unpaid capacity on the Medical and Scientific Advisory Council of the Massachusetts Down Syndrome Congress and on the Scientific Advisory Board for Inclusive Fitness®
- ○ I receive salary support for Down syndrome research

Lightning Round Presentation Outline:

- Background: what is known on Fitness in Down syndrome
- Pre-summit literature search
- Summit overview: who, what, where, when
- Development of Expert Recommendations: Delphi process
- Outcome: Fitness Recommendations, new scientific collaborations, future research directions
- Dissemenation of new guidelines

Definitions: Physical Activity vs Exercise vs Physical Fitness

★ **Physical activity** = Any bodily movement generated by skeletal muscles that results in caloric expenditure above resting rate

★ **Exercise** = a subcategory of physical activity; physical activity that is structure, planned, and done with the intent of providing health benefits

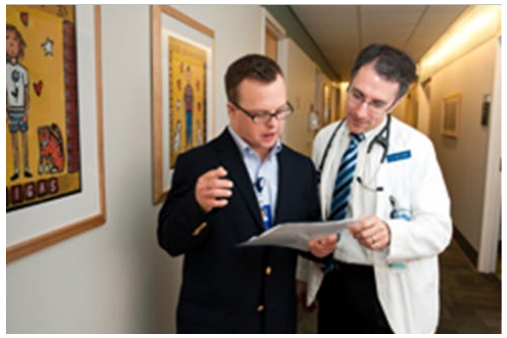
★ **Moderate-to-Vigorous Physical Activity (MVPA)** = a level of physical activity intensity, "*your heart is racing, you feel short of breath, you are sweating, you can talk but cannot sing or whistle*"

➢ Thus… all exercise is physical activity; not all physical activity is exercise

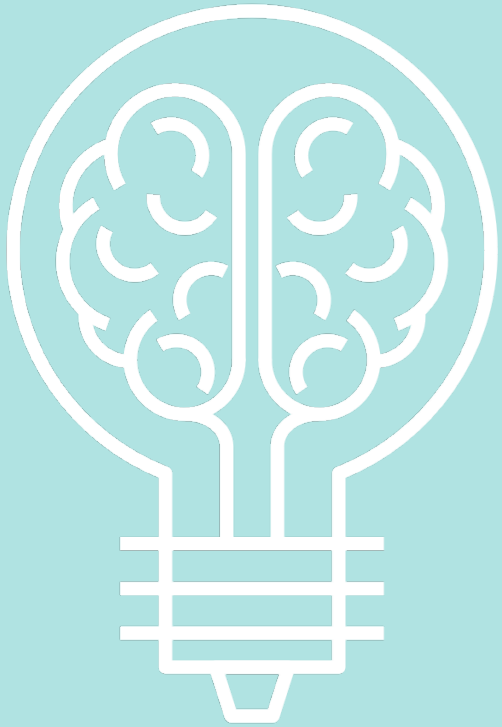
➢ Both have health benefits; *exercise* usually necessary to achieve MVPA intensity

★ **Physical Fitness** = A measurable state of health performance (endurance, strength, power, balance) achieved through physical activity and exercise

Physical Activity



Exercise



Background Information: “What was known?”

Clinical & Non-clinical Observations

- **Less likely to engage in physically activity**
- More likely to gain weight during late adolescence and by early adulthood
- More likely to have unhealthy eating behaviors
- Less likely to have opportunities for physical activity
- Frequent societal biases impacting opportunities for fitness
- Many possible barriers to fitness: transportation, companion, housing, boredom
- Unique anatomical and physiological characteristics (low muscle tone, lower metabolism and cardiovascular response)
- Delayed motor development, difficulties with coordination and balance
- Etc…

Existing Knowledge on Fitness in Down syndrome

Step 1: Overview of Approach

1. Literature Search (PubMed)
2. Artificial Intelligence (initial draft)
3. Human review

Literature Search

- 86 articles identified
- Created standardized criteria to catalogue each paper

A	B	C	D	E	F	G	H	I
Study Reference	**Type of Activity**	**Type of Study**	**Total Number of Participants**	**Country Where Research Was Done**	**Age of Participants**	**Duration of the Intervention**	**Major Outcomes of the Study**	**Quality/Certainty of Evidence**
Ptomey et al.	Physical activity promotion (comparing individual vs parent supported approaches).	Clinical trial investigating individual vs parent supported PA in adolescents with IDD (including DS).	116 adolescents (59 + 57 in groups).	United States (Kansas related).	Adolescents (likely 10-17 years).	Not explicitly stated in excerpt.	Assessed participant demographics and IDD diagnoses distribution across intervention groups. Compared outcomes between the two PA support approaches (specific outcomes not listed in excerpt).	Clinical trial design comparing two intervention methods (higher potential for causality). Moderate sample size (N=116 adolescents). Focuses on adolescents with IDD, including DS. Registered clinical trial.

- Used closed AI system (Notebook LM) to synthesize data from all the papers
- Used GRADE-based approach to rate the quality and strength of the evidence

GRADE: Grading of Recommendations Assessment, Development and Evaluation

Quality and Strength of Evidence

Weak	There is limited scientific evidence to support this recommendation. There is limited confidence in the estimated effect. The true effect might be substantially different from the estimated effect.
Moderate	There is a moderate amount of scientific evidence to support this recommendation. There is moderate confidence in the estimated effect. The true effect is likely to be close to the estimated effect, but there is a possibility that it is substantially different.
Strong	There is substantial scientific evidence to support this recommendation. There is a lot of confidence that the true effect lies close to that of the estimated effect.

Aerobic Activity: Evidence Base Synthesis

Existing Evidence

- Yields benefits for individuals with DS
- Individualized exercise programs have shown improvements in motor proficiency, including running speed and agility
- can positively impact executive function and memory (mixed results)
- Weight loss

Existing Recommendations

- **Children: American Academy of Pediatrics** recommends at least 60 minutes of moderate or greater intensity physical activity per day (not DS specific)
- **Adults: Physical Activity Guidelines for Americans** recommend at least 150 minutes of moderate-intensity or 75 minutes of vigorous-intensity aerobic activity per week

Limitations

- Children and adults with DS are not currently meeting the guidelines
- The optimal intensity, duration, and activity type need further study
- The effect on many health outcomes/co-occurring conditions unclear

Resistance Training (Muscle): Evidence Base Synthesis

Existing Evidence

- Yields improvements in muscle strength (both upper and lower limbs), functional capacity, and balance
- Can improve lean mass and bone mass
- Need for correct movement instruction, consistent supervision, and a gradual approach

Existing Recommendations

- **Children: None**
- **Adults: Physical Activity Guidelines for Americans** recommend engaging moderate-intensity RT at least 2 days per week

Limitations

- Unclear whether meeting recommendations
- The optimal intensity, duration, and resistance training activity type need further study
- Impact on health outcomes and co-occurring conditions is largely unknown

Balance : Evidence Base Synthesis

Existing Evidence

- Yields benefits for improving both static and dynamic balance, thereby theoretically reducing the risk of falls
- Exercise training yields positive impact on balance
- Examples of balance exercises studies in DS include standing on one leg, skipping and hopscotch, the use of balance equipment, and active gaming

Existing Recommendations

- **Children: None**
- **Adults: None**

Limitations

- Unknown what level of balance training children or adults with DS are receiving
- Unclear what level of balance individuals with DS achieve across the lifespan
- The optimal intensity, duration, and balance activity type need further study
- Impact on health outcomes is unknown

Summit Overview

SUMMIT AIM

To bring together leading scientists and clinicians from around the globe to discuss the latest research and therapies, promote knowledge exchange across the scientific community, and forge new collaborative opportunities in the field of physical fitness for individuals with DS.

Summit features: at-a-Glance…

Conference Duration:

2 days

Total in Attendance:

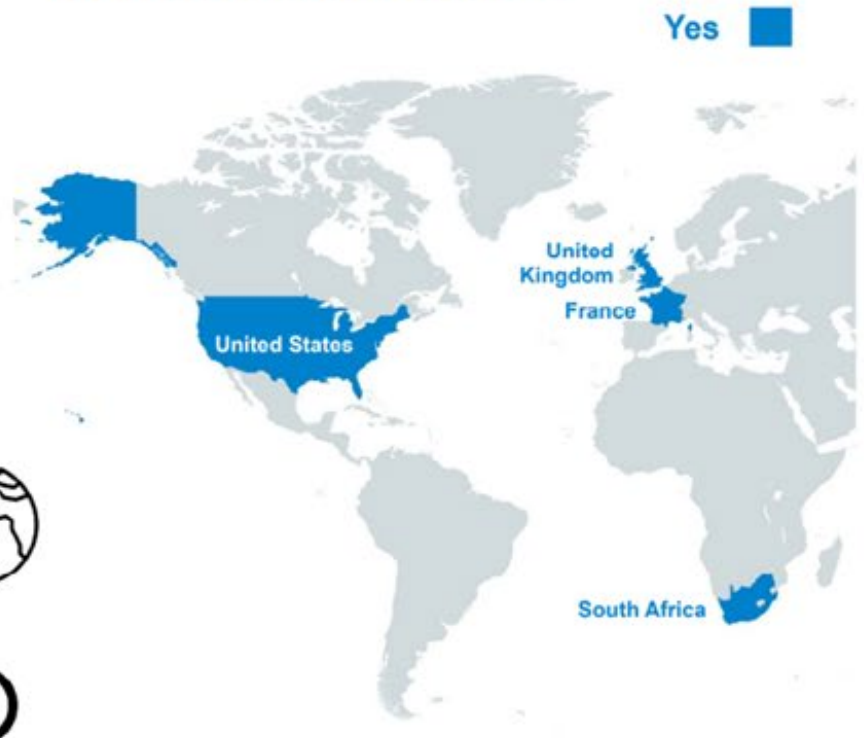
27

Speaker Demographics

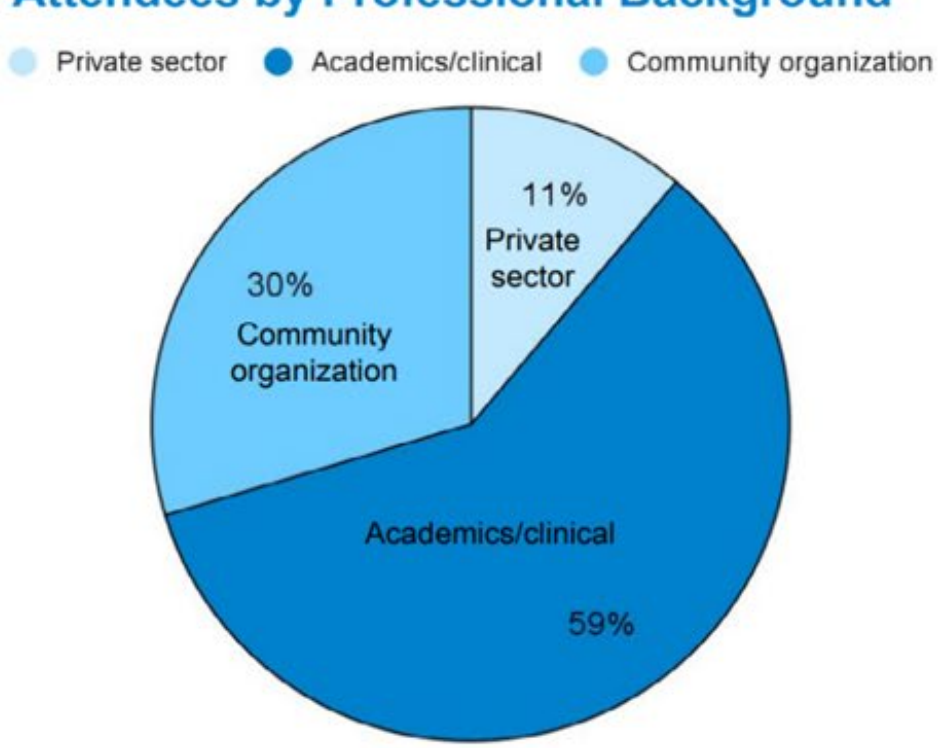
21%
International

43%
Female

Countries in Attendance



Attendees by Professional Background



Physical Fitness in Down Syndrome Summit: Overview

Pre-Summit:

- Start Delphi Process – initial voting

Day 1:

- Presentations

Day 2:

- Group-think
- Delphi Process

Post-Summit:

- Delphi Process completion
- information dissemination/manuscript preparation

Summit Presentations by Topic

Assessing Activity and QOL	Exercise Interventions	Functional Fitness & Aging	Exercise Physiology	Inclusive Fitness
Physical activity levels, preferences, barriers, and the role of provider counseling in promoting activity among individuals with DS.	Remote exercise program aimed at preventing Alzheimer's disease in adults with DS.	Muscle power as a key determinant of function and proposed interventions to support independence in aging adults with DS.	Physiological contributors to low aerobic capacity in DS, including fat mass, insulin resistance, and hormonal imbalances.	Insights from building an inclusive physical therapy practice for individuals with disabilities, including DS.
The Down Syndrome Health Measure (DSHM), a survey tool to assess health and physical activity impacts on quality of life.	MinDSets study data on how exercise impacts cognitive and physical function in adults with DS.	Longitudinal findings of age-related fitness declines and validated a DS-specific assessment tool.	Autonomic dysfunction—low HR, blunted sympathetic response—as a central factor in reduced exercise capacity.	AdaptX's model integrating clinical PT into inclusive fitness programs and community partnerships.
	Evidence on exercise benefits and proposed a gene–exercise study to explore personalized interventions.	The Mann Method PT framework to address musculoskeletal, vestibular, and endurance challenges across the lifespan.	Exercise physiology and cardiovascular considerations in adults with DS.	The impact of physical activity, particularly Special Olympics on the life of a person with DS.
			Photobiomodulation therapy as a novel tool for enhancing muscle repair and function.	

Presentations

Theme	Topics	Presenter
Activity and QOL	Physical activity, children and adults with DS	Nicolas Oreskovic
Activity and QOL	Health measurement in DS using surveys	Stephanie Santoro
Exercise Interventions	Remote exercise for the prevention of Alzheimer's Disease in DS	Lauren Ptomey
Exercise Interventions	Role of exercise in physical and cognitive attributes in adults with DS	Dan Gordon
Exercise Interventions	Effects of prescribed exercise on physical and cognitive health in DS	Don Keiller
Functional Fitness and Aging	Functional fitness in adults with DS - physical impairments that limit independence and quality of life	Kieran Reid
Functional Fitness and Aging	Physical therapy (PT) and PT-based exercise in DS	Sarah Mann
Exercise Physiology	Physical fitness in adults with DS: lab-based and clinical trials	Veronique Bricout—Serrurier
Exercise Physiology	Physiological mechanisms underlying reduced physical work capacity in DS	Bo Fernhall
Exercise Physiology	Summarized her research on physical activity, fitness, and cardiovascular health in adults with intellectual disabilities, particularly DS	Thessa Hilgenkamp
Exercise Physiology	Photobiomodulation therapy and muscle function	Nashwa Cheema, Joshua Tam
Inclusive Fitness	Establishing and building a business centered on providing inclusive physical therapy options for individuals with disabilities, including DS	Greg Austin
Inclusive Fitness	Expanding inclusive fitness pathways for individuals with DS	Brendan Aylward, Chris Joyce
Inclusive Fitness	Personal story of living with DS, the important role of physical activity in life	Melissa Reilly

Delphi Process: Structured Development of Expert Recommendations

Delphi Process: Definition

Historical Origin

- Named after Greek Oracle of Delphi who could predict the future
- Developed by RAND Corporation in 1950s to forecast technology's impact on warfare – named "*delphi*" to signify the method's purpose of eliciting expert "prophetic" insight and consensus regarding future events

Current Scientific Approach:

- A **structured**, **iterative** research technique used to gain **consensus** among a panel of **experts** on complex information without established gold standards, often with the intent of forecasting
- Process involves multiple rounds of **anonymous**, written, or electronic questionnaires, with feedback provided between rounds, allowing participants to refine their opinions based on the group's collective input

Δελφοί

Delphi Process: Details

- 85% agreement threshold requirement set *a priori* to achieve recommendation status
- voting process was anonymous and iterative
- opportunity for feedback at each round
- anonymized analytics
- results disseminated to all participants after each round of voting

Delphi Process: Timeline Overview

- 23 experts participated in Delphi process
  - option to abstain from voting during each round on any recommendation
- First round of asynchronous electronic voting pre-summit
- 1 round of synchronous on-site voting during the summit
- 2 post-summit rounds of asynchronous electronic voting
- Total: 4 rounds of voting required to achieve consensus

Summit Outcomes

Oreskovic NM, Austin G, Aylward B, Boer P, Bricout VA, Cheema N, Das A, Fernhall B, Fleming R, Florez C, Gordon D, Spognardi AG, Hilgenkamp T, Hillerstromm H, Joyce CT, Keiller D, Kelly L, Komyerov J, Lincoln AE, Mann S, Murray L, Pickard K, Ptomey LT, Reid KF, Reilly M, Rhondeau M, Santoro SL, Stanish H, Tam J, Torres A, Skotko BG. **The International Summit on Health Benefits of Physical Fitness for People With Down Syndrome: Current Science, Gaps, Priorities, and Research Opportunities.** *Am J Med Genet A*. 2026 Feb;200(2):535-544. doi: 10.1002/ajmg.a.64256. PMID: 40977151.

American Journal of Medical Genetics Part A

WILEY

AMERICAN JOURNAL OF medical genetics PART A

CONFERENCE REPORT

The International Summit on Health Benefits of Physical Fitness for People With Down Syndrome: Current Science, Gaps, Priorities, and Research Opportunities

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ABSTRACT

The summary paper reports on and highlights the scientific discussions and development process for new expert-recommended physical fitness guidelines for individuals with Down syndrome that occurred at the inaugural International Summit on Health Benefits of Physical Fitness for People with Down Syndrome (ISFDS). The Summit was a two-day event held in May 2025 at the Massachusetts General Hospital in Boston that brought together leading international scientists, clinicians, self-advocates, community services and industries, and local and national advocacy organizations to discuss the latest research, therapies, and collaborative opportunities in physical fitness for individuals with Down syndrome. Day 1 focused on the current state of the science and the identification of research gaps; Day 2 featured working groups dedicated to developing collaborations, planning future research, and creating expert clinical guidelines on physical fitness in children and adults with Down syndrome using a Delphi approach.

Abbreviations: DS, Down Syndrome; ISFDS, International Summit on Health Benefits of Physical Fitness for People with Down Syndrome; MGH DSP, Massachusetts General Hospital Down Syndrome Program.

Physical Fitness in DS Guidelines: overview

Recommendations for fitness health focus on 3 core components:

- **Aerobic**
- **Muscle**
- **Balance**

Physical Fitness Recommendations for DS: Guidelines

TABLE 1A | Recommended guidelines for promotion of physical fitness for persons with DS.

Age (years)	Category	Recommendation	Strength of evidence
5–12	Aerobic	Daily movement encouraged, with a goal of at least 30 min or more at a moderate or greater intensity	Weak to Moderate
	Muscle	Daily muscle use, including any combination of play activities, sports that use body weight, or full body exercises	Weak to Moderate
	Balance	At least twice weekly non-structured exercises, multi-component physical activities, or physical play activities	Moderate
13–17	Aerobic	Daily movement encouraged, with a goal of 30 min or more at a moderate or greater intensity	Weak to Moderate
	Muscle	At least 3 days of muscle use, including any combination of play activities, sports that use body weight, or full body exercises	Moderate
	Balance	2–3 times per week; 15–20 min sessions	Moderate
18+	Aerobic	Daily activity with a goal of achieving at least 150 min per week of moderate or higher intensity movement	Weak to Moderate
	Muscle	2–3 times per week; 2–3 sets of 6–12 repetitions at moderate to hard intensity; 30–60 min sessions	Moderate to Strong
	Balance	2–3 times per week; 20–30 min sessions	Moderate

Oreskovic et al., 2025

Physical Fitness Recommendations for DS: Examples

TABLE 1B | Examples of physical fitness exercises for persons with DS by age and category.

Age (years)	Category	Examples
5–12	Aerobic	Playground activities (tag, jungle gym, hopscotch), individual sports (martial arts, swimming), team sports (soccer, basketball, kickball)
	Muscle	Bodyweight, resistance bands, light weights, obstacle courses
	Balance	Playful activities like hopping, skipping, single-leg stance, balance beam, throwing and catching
13–17	Aerobic	Running, stationary bicycle, outdoor bicycle, swimming, hiking, dance, team sports, individual sports, whole body exercise, roller skating/inline skating/skateboarding, cross-country skiing
	Muscle	Bodyweight, resistance bands, gym equipment, obstacle courses
	Balance	Tandem stance, single-leg squats, unstable surfaces, yoga, dance, circus and gymnastics activities, lateral tilts, front-to-back tilts, over-under passes with ball, throwing and catching
18+	Aerobic	Brisk walks, running, stationary bicycle, outdoor bicycle, rowing, swimming, water aerobics, interval training, dance, hiking, individual sports, whole body exercises, roller skating/inline skating/skateboarding, cross-country skiing
	Muscle	Machines, free weights, resistance bands, bodyweight
	Balance	Heel-to-toe walking, tandem stance, single-leg stance, weight shifts, balance boards, Tai Chi, adapted dance, gymnastics, Pilates, walking on low balance beam, lateral tilts, front-to-back tilts, over-under passes with ball

Oreskovic et al., 2025

Age 5-12 years: Fitness Recommendations

Category	Recommendation	Strength of Evidence
Aerobic	Daily movement encouraged, with a goal of at least 30 minutes or more at a moderate of greater intensity	Weak-Moderate
Muscle	Daily muscle use, including any combination of play activities, sports that use body weight, or full body exercises	Weak-Moderate
Balance	At least twice weekly non-structured exercises, multi-component physical activities, or physical play activities	Moderate

Age 5-12 years: Fitness Examples

Category	Examples
Aerobic	Playground activities (tag, jungle gym, hopscotch), individual sports (martial arts, swimming), team sports (soccer, basketball, kickball)
Muscle	Body weight, resistance bands, light weights, obstacle courses
Balance	Playful activities like hopping, skipping, single-leg stance, balance beam, throwing and catching

Age 13-17 years: Fitness Recommendations

Category	Recommendation	Strength of Evidence
Aerobic	Daily movement encouraged, with a goal of 30 minutes or more at a moderate of greater intensity	Weak-Moderate
Muscle	At leas 3 days of muscle use, including any combination of play activities, sports that use body weight, or full body exercises	Moderate
Balance	2-3 times per week; 15-20 minute sessions	Moderate

Age 13-17 years: Fitness Examples

Category	Examples
Aerobic	Running, stationary bicycle, outdoor bicycle, swimming, hiking, dance, team sports, individual sports, whole body exercises, roller skating/inline skating/skateboarding, cross-country skiing
Muscle	Body weight, resistance bands, gym equipment, obstacle courses
Balance	Tandem stance, single-leg squats, unstable surfaces, yoga, dance, circus and gymnastic activities, lateral tilts, front-to-back tilts, over-under passes with ball, throwing and catching

Age 18+ years: Fitness Recommendations

Category	Recommendation	Strength of Evidence
Aerobic	Daily activity with a goal of achieving at least 150+ minutes per week of moderate of higher intensity movement	Weak-Moderate
Muscle	2-3 times per week; 2-3 sets of 6-12 repetitions at moderate to hard intensity; 30-60 minute sessions	Moderate-Strong
Balance	2-3 times per week; 20-30 minute sessions	Moderate

Age 18+ years: Fitness Examples

Category	Examples
Aerobic	Brisk walks, running, stationary bicycle, outdoor bicycle, rowing, swimming, water activities, interval training, dance, hiking, individual sports, whole body exercises, roller skating/inline skating/skateboarding, cross-country skiing
Muscle	Machines, free weights, resistance bands, body weight
Balance	Heel-to-toe walking, tandem stance, single-leg squats, weight shifts, balance boards, Tai Chi, adapted dance, gymnastics, Pilates, walking on low balance beam, lateral tilts, front-to-back tilts, over-under passes with ball

Aerobic: Individual Sports

Muscle: Resistance Bands

Mann Method
PT and Fitness, PLLC

Muscle: Machine Weights

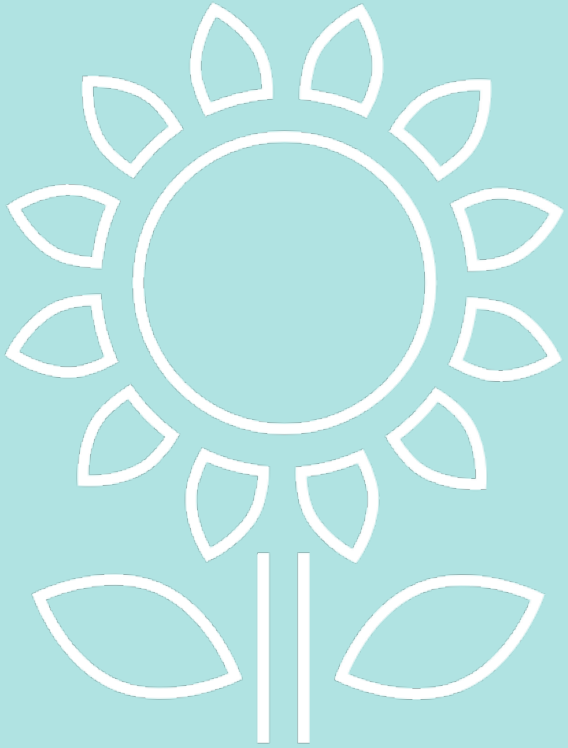
Balance: Lateral Tilts

Mann Method
PT and Fitness, PLLC

Balance: Over-Under Pass

Balance: Modified single leg squats

Mann Method
PT and Fitness, PLLC



Thank you

Q&A

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