



Exercise in PWS: motor barriers and possible solutions

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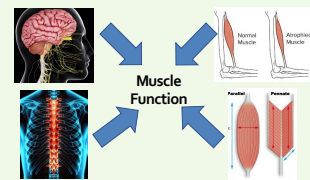
Presentation Outline

- Presentation goal: to provide caregivers and providers key background explaining motor challenges in PWS and evidence-based exercises to work with these challenges
- Topics for coverage:
 - Neuromuscular challenges
 - Muscle quality and activation
 - Coordination
 - Sensorimotor challenges:
 - Balance
 - Biomechanical challenges:
 - Gait and common movements such as sit-to-stand transitions
 - Behavioral challenges
 - Recommendations for physical activity during adulthood: what, for how long and how often?

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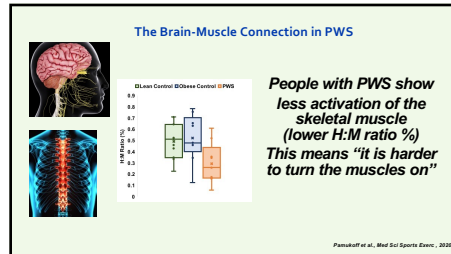
Factors that Influence Muscle Function



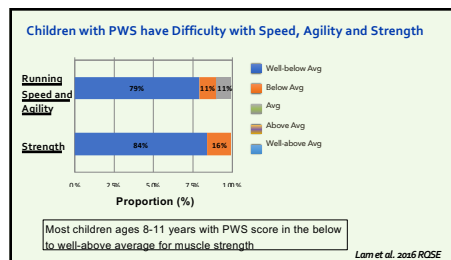
Muscle Function

Pennings et al., Med Sci Sports Exerc, 2000

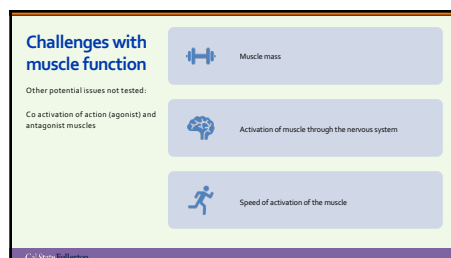
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Muscular Strength Training Considerations

Strength Training is Feasible and Effective

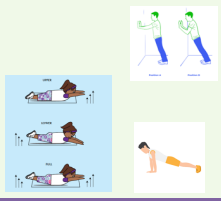
Should include adequate goals

Include exercises that can be regressed (wall push up) and progressed (full push up)

The exercise must be successfully done with good form and at least include 6-10 repetitions at the beginning of the program for one set

Complete exercises at least twice a week

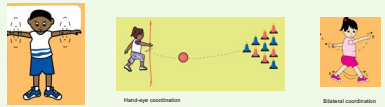
Other activities: Pilates, Aquagym with water weights



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Difficulties with Upper Limb Coordination, Hand-eye Coordination and Bilateral Coordination



Upper limb coordination

Hand-eye coordination

Bilateral coordination

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Activities that Stimulate Body Coordination

Example of group & individual activities/classes

- Martial arts (karate, taekwondo)
- Yoga
- Zumba
- Dance
- Tai-Chi
- Horse-back riding
- Bowling/Swimming/Sports



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Postural Control

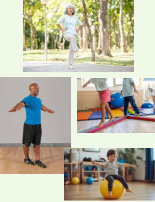
Balance: is the process of controlling the body center of mass with respect of its base of support whether when moving or being still.

Balance requires inputs from the visual, the somatosensory and the vestibular systems.

During childhood the somatosensory and the vestibular systems are still in development.

Posture: refers to the biomechanical alignment of all body parts as well as the orientation of the body in the environment

When we stand we are maintaining postural control by limiting sway in different directions



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Postural Control

When children with PWS ages 8-11 y are matched with children with neurotypical development, they present less postural control and more chances of falling when they need to rely on the vestibular system for maintaining balance.

When adults with PWS (n=10) are matched with adults with neurotypical development, they present less postural control and more chances of falling when they need to rely on the vestibular system for maintaining balance.



Debra J. Rose, Ph.D.
testing a child for balance

Reardon, C., Lerner, M., Wilson, G., Kiehl, J., & Kiehl, J. (2010). The effects of PWS on postural control: A study of 10 individuals with PWS. *Journal of Autism and Developmental Disorders*, 40(10), 1351-1358.

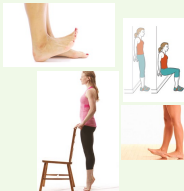
Reardon, C., Lerner, M., Wilson, G., Kiehl, J., & Kiehl, J. (2010). The effects of PWS on postural control: A study of 10 individuals with PWS. *Journal of Autism and Developmental Disorders*, 40(10), 1351-1358.

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Home-based program for 6 months for 11 adults with PWS

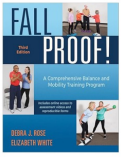
- Muscular strength in ankle flexion and extension (17% increase)
- Gait improvement: 112.57 vs. 117.25 steps/min
- No change in static balance



Vismara et al. 2012 Res Dev Disab 36:1271-1279
Carpenter et al. 2011 Neurology 76:1015-1020

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Evidence-based Programs that Stimulate Static and Dynamic Balance



Programs should address:

- Muscular strength
- Flexibility
- Gait (Walking)
- Multisensorial training

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Activities that Stimulate Static and Dynamic Balance





Dual task: catching a ball while standing on unstable surface

Unstable surface

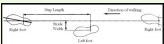
Walking on reduced support surface

- Martial arts, Tai Chi, Yoga
- Dancing
- Playground games
- Reduce/remove/engage vision on a task
- Unstable/compliant/moving surfaces
- Combination of unstable/compliant surface with dual tasking

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Altered Gait (Walk) Mechanics



Adults with PWS self-select to walk at slower speeds than those without PWS.

They take shorter and wider steps. They spend a longer time in double limb support, likely reducing the load placed in a single limb.

They have a more rigid and stable walk.



Derek Pamukoff, Ph.D.

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Exercises to Help with Generating Greater Force during Walking

Heel Raises

- Heel raises work on ankle plantar flexion.
- Heel Raises with and without support.
- Begin with two legs stance and progress to single leg for greater workload.
- Can use external loads such as ankle weights or a loaded backpack to increase the load.

Sample Heel Raises with support

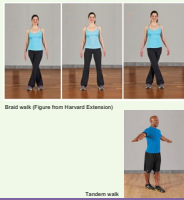


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Exercises to Help with Walking Faster and more Flexible

Walking in different directions (forward, back)
Start and stop abruptly the walk
Change directions in the walk path
Alter the base of support such as narrow, wide steps, walking on heels, walking on toes
Tandem walk or braid walk



Braid walk (Figure from Harwood Osterman)

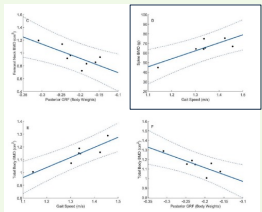
Tandem walk

Exercises from: Rose D.J, White K, Falliswell. A Mobility and Balance Training Program. 2012 Third Edition, Human Kinetics, Champaign, IL.

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Bone Parameters Associations with Gait in Adults with PWS (n=10)



Faster walk is associated with better bone density

Bullington et al. 2019. Bone Reports

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Walking or aerobic exercise

Adults with PWS can walk >20 min without stopping, even complete up to 10 km if they follow a progression.

If the person is not active: begin with 4 sessions 20-35 min long throughout the day. The aim is to get 60 min in a day not 60 min in one time!

If the person is already active: begin with the highest amount of time they can exercise for and progress by adding 5% every two weeks until they can complete 60 min total.

Progress to jogging/running.

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Teens and Adults Program

Balance and Strength Days 2 days a week (~30-60 min):

- 5-10 min of exercises to warm-up
- Balance exercises
- Resistance training exercises
- 8 exercises targeting major muscle groups
- 6+ repetitions for 2 sets or more

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Sample At Home Exercise Selection and Progression used with Teens and Adults Down Syndrome

Complete 2 -3 rounds of exercises in a circuit format
Each exercise repeated 6-12 times based on the progression.
Rest for 1 min in between exercises and rounds

Day	Target Muscle Group	Included Exercises
One	Upper body	Backpack press, backpack curls, Y-T's
	Lower body	Chair taps, chair-standing foot tap, crazy jacks
	Core	Bird-dog, sit-ups
Two	Upper body	Backpack drags, backpack curls, push-ups, Super-You
	Lower body	Heck-squat side step, heel raises, vertical jumps
	Core	Side planks
Three	Upper body	Backpack curls, push-ups, Super-You
	Lower body	Chair taps, crazy jacks, heel raises
	Core	Sit-ups

Rubin, Clark, Lam, Young, Britz, Fisher. J Appl Physiol. 2021;124(10):e10165.

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Growth Hormone Replacement Therapy: It Matters

GHRT improves muscle mass which directly contributes to force and strength development

GHRT contributes in early childhood to improvement in motor skills

GHRT contributes in adulthood to increased muscular strength & aerobic capacity and stamina

Leiferman GJ, Minkoff A, Capodaglio R, et al. Skeletal muscle characteristics and motor performance after 3-year growth hormone treatment in adults with Prader-Willi syndrome. J Clin Endocrinol Metab. 2014;96(11):3314-3321. doi:10.1210/clinem.2013.3027

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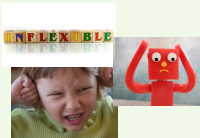
Considerations to Help the Individual with PWS Succeed

- 1 Set achievable goals
- 2 Make physical activity or exercise part of the daily "FUN" routine
- 3 Include physical activity or exercise as part of daily activities (routine)
- 4 Exercise or do activities as a group. Co-activity is a powerful motivator

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Behavioral Challenges

- Difficulties with stamina and execution of exercises may trigger an emotional outburst because the goal is inadequate
- Keep the routine of exercise
- Consider option for activities: no activity is not an option
- Find facilities that are willing to provide the service needed considering the person with PWS behaviors and needs



IN FLEXIBLE

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Leveraging Group Homes

Group Homes are ideally set up to provide tailored programming adequate for adults with PWS

- Need Exercise Specialist to plan and oversee the activities
- Credentials could include ACSM Exercise Specialist, Physical Therapist, Exercise Specialist with FallProof or other balance certification
- Provide access to remote/web programs facilitated synchronously or asynchronously

Group Homes need to be screened and modified to built a safe space that prevents falls

- Including access ramps, handrails, indications of steps, decluttered environments
- Good lighting at all times but specifically at night for individuals to access restrooms safely

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Thank you for your attention!!!

My contact: drubin@fullerton.edu

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