



**IPWSO**  
International  
Prader-Willi Syndrome  
Organisation

**Caregiver ECHO**  
15<sup>th</sup> December 2021

# The Power of Exercise for People with PWS

Georgina Loughnan

Prader-Willi Syndrome Clinic

Royal Prince Alfred Hospital

Sydney, Australia



# Fit for Life, through Exercise



# Physical Features seen in People with Prader-Willi Syndrome (PWS)

## Clinical Features

- ❑ Lower muscle tone
- ❑ Decreased % muscle
- ❑ Reduced muscle strength

## Functional Impact

- ↓ resistance to movement
- Loose muscles
- Less stable joints
- Poor balance
- Reduced total daily energy output
- Reduced fat burning potential
- Poor posture
- Hypoventilation
- Reduced respiratory fitness
- Reduced physical capacity
- Prone to daytime sleepiness
- Reduced motivation

# Physical Features in PWS <sub>2</sub>

## Clinical Features

- ❑ Increased % body fat

## Functional Impact

- Increased fat storage ability
- Gain fat readily
- Increased cardiac risk
- Obstructive sleep apnoea risk
- Reduced energy intake requirement  
*dieting* ➡ *loss of muscle loss*  
*(if not exercising)*

# Physiological Features in PWS

## Clinical Features

- ❑ Hypothalamic ↑ hunger / ↓ satiety
- ❑ Reduced hormonal maturation
- ❑ Desire sameness

## Functional Impact

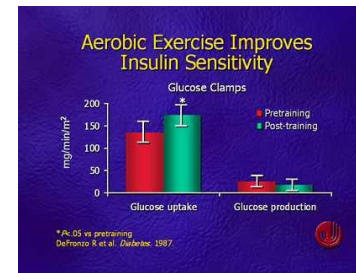
- Constant food focus
- Hyperphagia
- ↑ risk of osteoporosis
- Dislike new interventions
- *Like consistency*
- *Regularity increases compliance*

# The Importance of Exercise

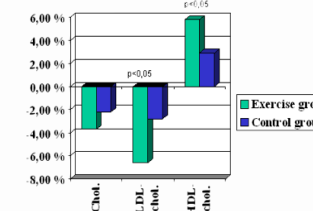
- Musculo-skeletal improvement
  - Muscle strength
  - Joint stability
  - Bone density
- Achievement of motor milestones
- Weight management
- Cardio-respiratory fitness
- Vascular health
- Mood - endorphins / BDNF / cannabinoids
- Distraction from food focus

# The Improvement of Obesity-related Co-morbidities

- Diabetes -     ↑ insulin sensitivity
- Hypertension
- Circulation
- Hypoventilation / OSA
- Oedema / lymphodema
- Hypercholesterolaemia -     ↑ HDL  
   ↓ LDL  
   ↓ Triglycerides



Effect of Impact Exercise on Cholesterol levels  
12 month follow-up



Ref. Vainionpää et al. Medicine and Science in Sports and Exercise, May 2007

# Exercise Picture

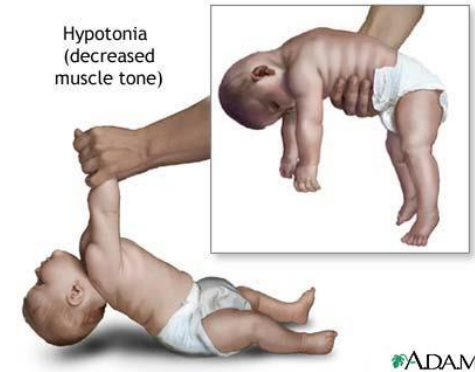
- Regular
- Aerobic & strengthening
- Low to moderate intensity
- Incorporated into daily routine
- One to one / group / fun / incidental
- **Not** an *optional extra*



# Where to Start

## □ Childhood

- Sensorimotor stimulation
- Joint alignment
- Supported weight bearing
- Gross motor skills / coordination
- Achievement of motor milestones

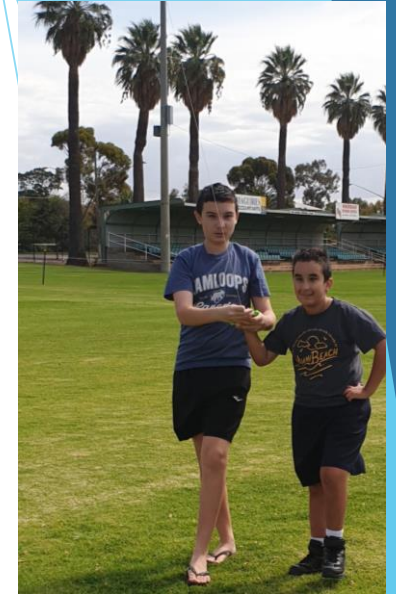


- ❖ Physical Therapy
- ❖ Occupational Therapy
- ❖ Speech Therapy





# Physical Fitness & Fun



**Family and carer  
involvement**

# Part of Life

## □ Adolescence / Adulthood

- Muscle strength & fitness
- Physical capacity
- Prevent or manage co-morbidities
- Weight management
- Bone density
- \*Mood - endorphins, BDNF
- Reduction of boredom and food focus

# Getting Started

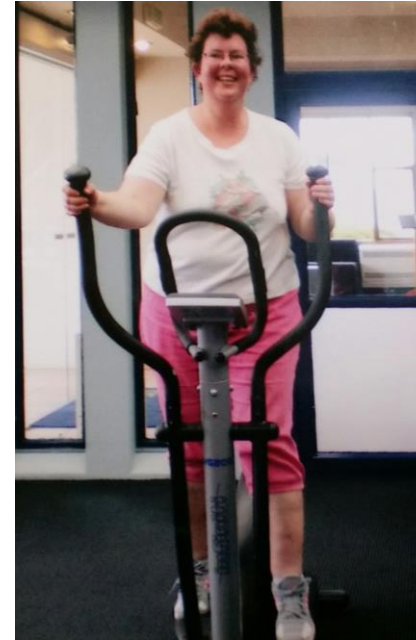
- 10 -20 mins
- 1-2 per day (x 6 days per week)
- Add to “work out” time
- Physical therapist / personal trainer
- Extra incidental activity
  - park the car further away from destination
  - walk/cycle rather than travel by car
  - use stairs rather than lift or travelator
  - walk the long way around to school / work
  - physically active outings



# Effective Exercise 1

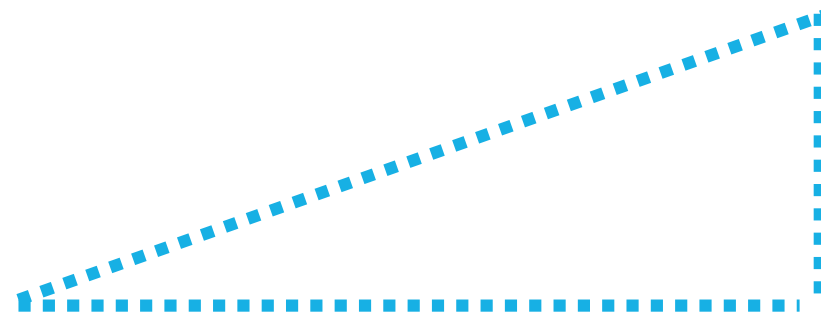
## ☐ Aerobic

- 30-60 minutes
- 5-6 days per week
- Before a meal or snack
- Supported or supervised
- Examples
  - walking / treadmill
  - cycling / air walker
  - swimming / water exercise
  - dancing / video games
  - sport / play / outings



# Intensity of Exercise

□ PER



Hot	1	2	3	4	5
Puffed	1	2	3	4	5
Sweaty	1	2	3	4	5
Exhausted	1	2	3	4	5

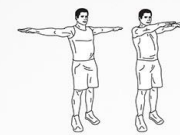
# Effective Exercise 2

## ☐ Strengthening

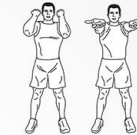
- Specific muscle groups
- Weighted/resisted arm exercises
- Bush / sand / rock walking
- Upper body & trunk exercises
- Ball play - throw/catch/bounce
- Up & down stairs
- Incidental activities - tidying room  
cleaning  
hanging out washing



10 knee push-ups



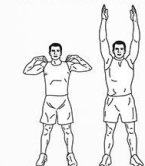
10 arm extensions



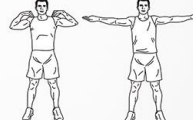
10 bicep extensions



10 knee push-ups



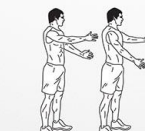
10 shoulder taps



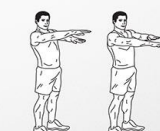
10 side shoulder taps



10 knee push-ups

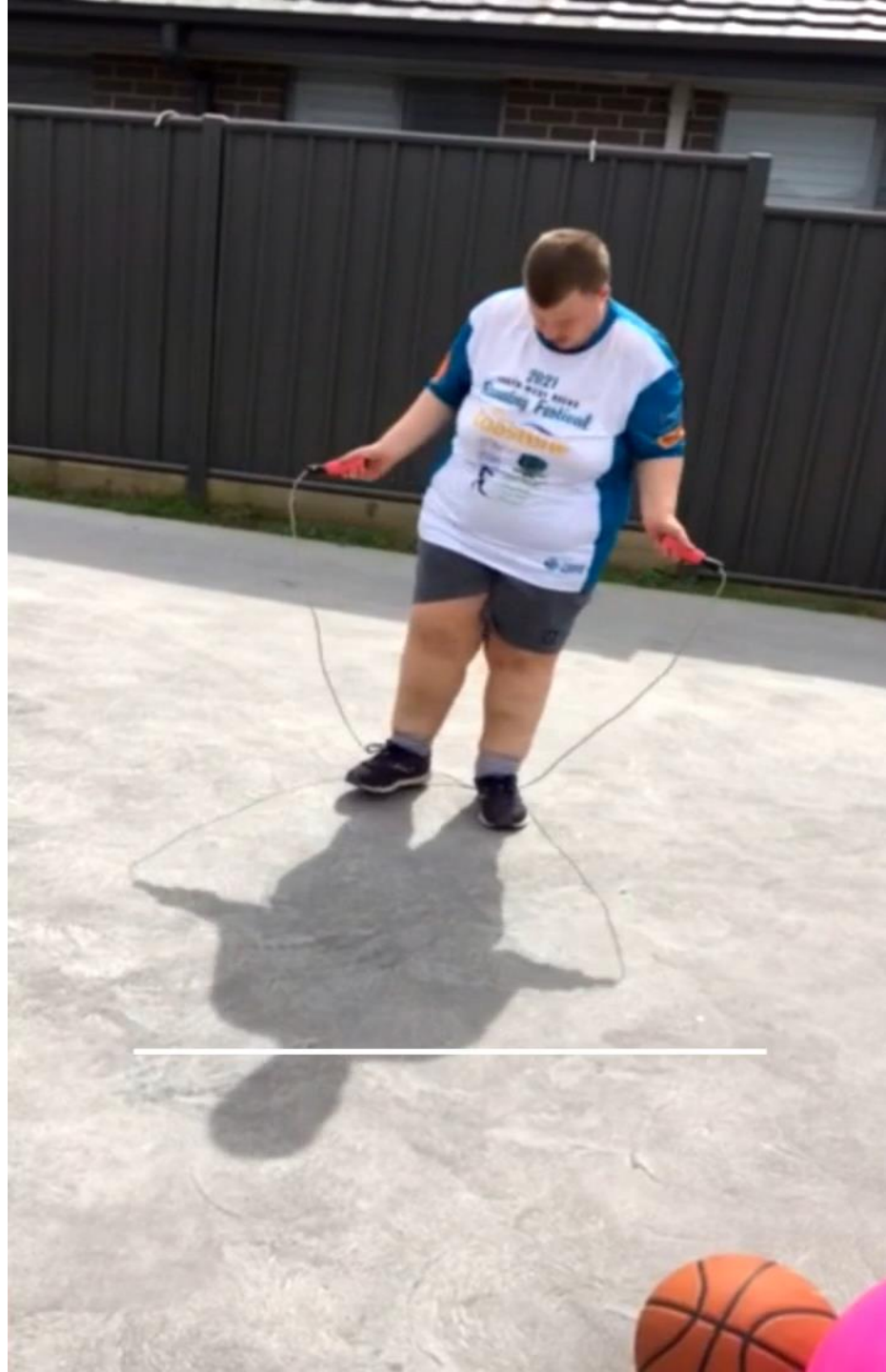


10 scissor chops



10 arm scissors





# Warm-up and Cool down

- Slow rhythmic movement ± stretches
- 3-5 mins slow start/finish of exercise
- To prevent soft tissue injury
- To prevent sudden change in BP

# Encourage Good Posture

## *Remind person to:*

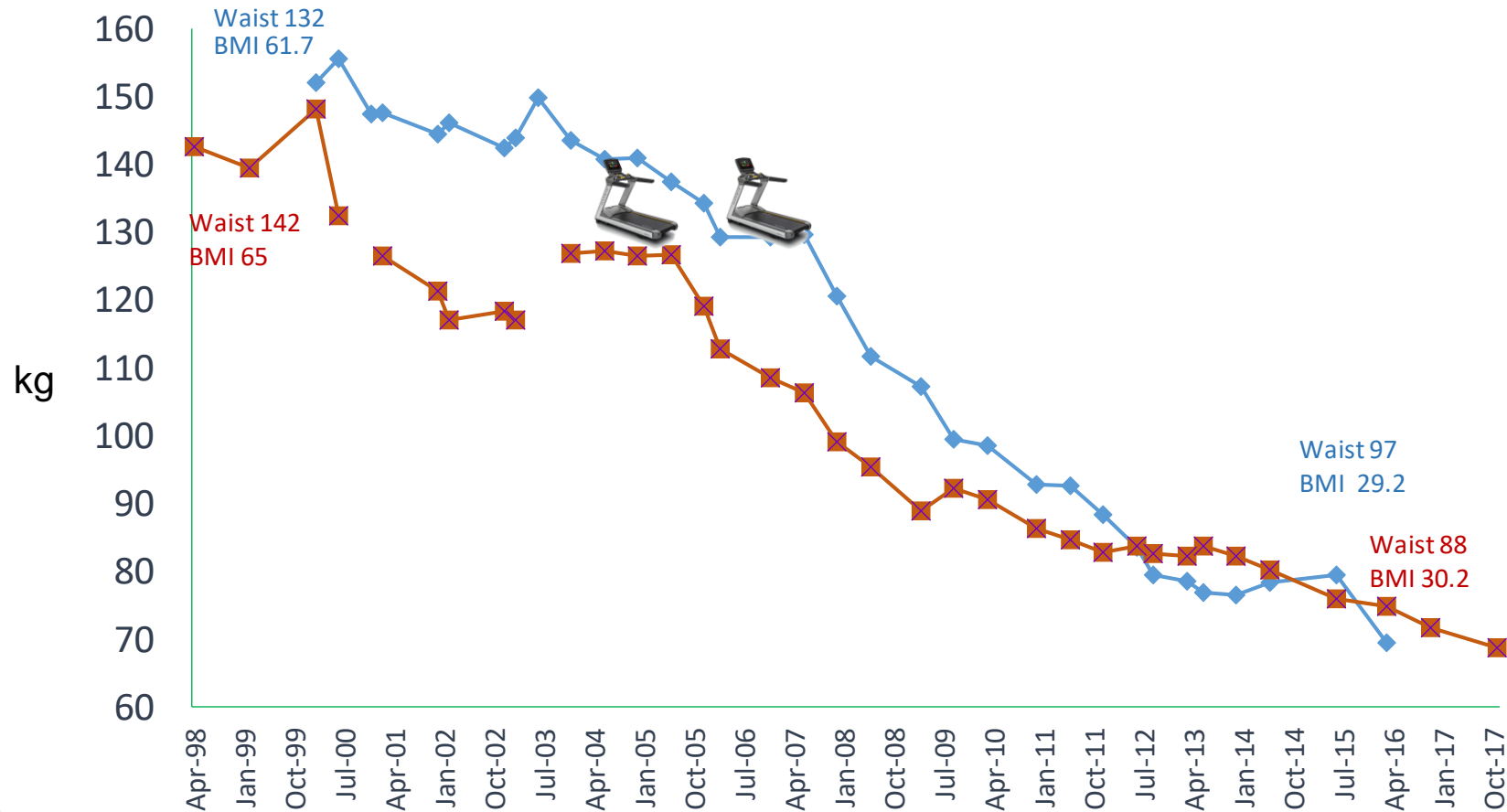
- Lift head up when talking/walking
- Keep a straight back / “walk tall”
- Sit up straight in the chair
- Elbows at table height

# Case Examples

SB(-79.5kg) & DB(-86.3kg)

“The measure of individual freedom  
(in Prader-Willi syndrome) correlates with body weight”

- Prof Andrea Prader



Waist (cm) BMI (kg/m<sup>2</sup>)





# Maintained Fitness

Day	Activity	Duration
<b>Monday</b>	Mauai Thai <i>or</i> Special Olympics swimming <i>or</i> Dog walking	60 mins 60 mins 60 mins
<b>Tuesday</b>	Gym- X trainer & weights	60 mins
<b>Wednesday</b>	Walk on treadmill at home	40 mins
<b>Thursday</b>	Gym <i>or</i> treadmill at home	45-60 mins
<b>Friday</b>	Dog walking, washing and feeding	90 mins
<b>Saturday</b>	Walks on treadmill at home	40 mins
<b>Sunday</b>	Gym - Tough Class	45 mins

**August 2021**

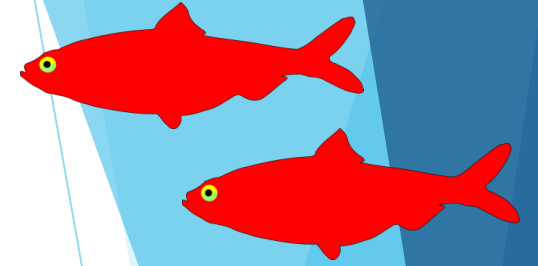
**Age: 28 yrs**

**Weight: 72 kg**

**BMI: 23.5 kg/m<sup>2</sup>**

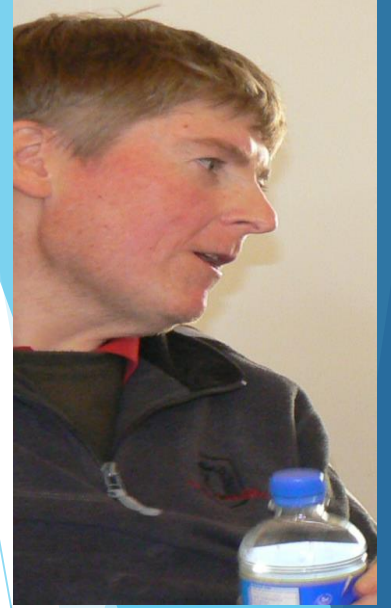
**Waist: 88 cm**

# Motivation Starts with You



- R(ed)      respect
- C          challenge
- A          acquired agreement
- R          responsibility
- R          rewards
- P          praise
- S          security





***exercise works...***



# References

- ❖ Daniela A Rubin, Kathleen S Wilson, Marilyn Dumont-Driscoll, Debra J Rose. **Effectiveness of a Parent-led Physical Activity Intervention in Youth with Obesity** *Med Sc Sports Exerc* 2019 Apr; 51 (4): 805-813
- ❖ Javier S Morales, Pedro I Valenzuela, Helios Pareja-Galeano, Cecilia Rincon-Castanedo, Daniela A Rubin, Alejandro Lucia. **Physical Exercise and Prader-Willi Syndrome: a Systematic Review** *Clinical Endocrinology* 2019;90:649-661
- ❖ Hee Joung Joung, In Soo Lim, **Changes in body composition, blood lipid profile, and growth factor hormone in a patient with Prader-Willi syndrome during 24 weeks of complex exercise” a single case study** *J Exerc Nutrition Biochem* 2018;22(1): 035-050
- ❖ Urs Eiholzer, MD, Yves Nordmann, MD Dagmar L’Allemand, MD, Michael Schlumpf, Silva Schmid, PhD and Katrin Kromeyer-Hauschild, MD. 2003 **Improving Body Composition and Physical Activity in Prader-Willi Syndrome** *J Pediatrics* 2003; 142:73-7
- ❖ Cynthia L Lewis. PT. PhD. **Prader-Willi Syndrome: A Review for Pediatric Physical Therapists** *Pediatric Physical Therapy* 2000; 87-95
- ❖ Kristy Reid, Peter Davies. **Exercise and Physical Activity for Children with Prader-Willi Syndrome** *Children’s Nutrition Research Centre - The University of Queensland (IPWSO Website)*