

RaceRunning: improving health and wellbeing in people with cerebral palsy



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Mrs Dawn Pickering (Cardiff University)

Mr Rob Henshaw (Quest88 Ltd)

Session overview

- Race-runners (RR's) / running-bikes (RB's)
- Impact of RR's on health
- Impact of RR's on wellbeing
- Practical demo (how to set up a RR)
- Q & A

Race runners / running-bikes

- 3 wheeled frame with handlebars, saddle and thoracic support
 - Propelled forward by feet
 - Various postural support accessories
- For individuals with mobility/balance disorders
- Developed in Denmark in 1989
 - Connie Hansen (OT & Paralympian)



Race runners / running-bikes

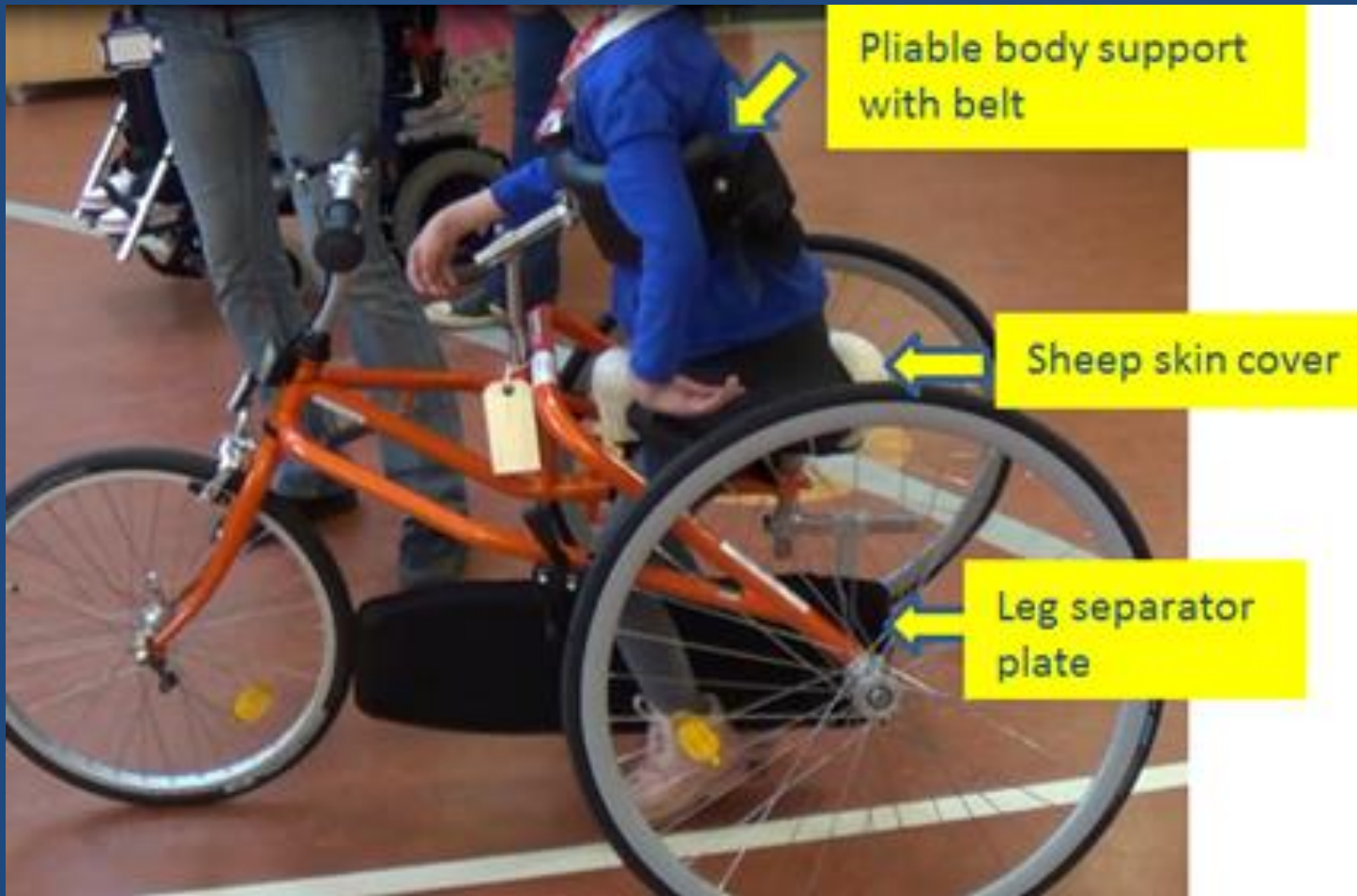
- Initial construction 1989
- and now www.racerunning.org
 - International disability sport (events 40m – 5000m)
 - **2011** introduced to International Wheelchair & Amputee Federation Games (IWAS)
 - **2012** included in 1st European Paralympic Youth Games
 - **2014** formal negotiations between IPC and CPISRA/Race Running
 - Active race running in 15 countries
 - CP Sport running taster days

Race runners / running-bikes

- Sport
- Therapy
- Daily living



Accessories for therapy sessions



Extra padding / accessories used during therapy sessions



Can running bikes be used to
improve health & wellbeing?

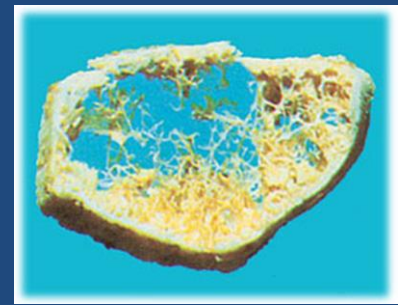
Research on RR's/RB's



- Very limited published literature
 - O'Donnell et al (2010) - Belgium
 - Metabolic responses to sustained exercise/CP ISRA classes ($n=9$ athletes CP1 to CP6)
 - Van Schie et al (2015) - Holland
 - Feasibility study, $n=50$ children with differing diagnoses (included GMFCS levels III & IV)
 - Bryant et al (2015) - UK
 - Pilot study, $n=15$ children with CP (GMFCS levels IV & V)



Background



- During childhood weight-bearing activities are required to stimulate the normal development of bone
- Children with cerebral palsy (particularly non-ambulant) have reduced bone density and increased risk of fracture
- Evidence shown positive effect of weight bearing exercise on lower limb bone health in 'typically' developing children
- Limited evidence on effect of exercise on bone health in non-ambulant children with cerebral palsy

Modes of exercise

- Limited opportunity to exercise for non-ambulant children with CP
 - Activities at school
 - Stretching
 - Trikes (adapted)
 - Swimming
 - Horse riding
- ‘Walkers’ are often bulky, heavy to manoeuvre
- Lessons learnt from earlier exercise interventions
 - Need for fun/enjoyable opportunities to enhance participation, fitness & improve bone strength



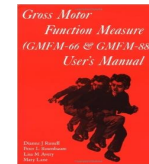
Non-weight bearing activities

Pilot study

- To investigate if running bikes are a feasible and enjoyable mode of weight-bearing exercise for non-ambulant children with CP (GMFCS levels IV & V)
 - 12 week intervention
 - 3 x week; school based
 - Outcome measures
 - Week 0 and and repeated Week 12

Outcome measures

- Ability to use the running bikes
- Feedback from the users
- Standing ability (GMFM-88D)
- Ultrasound bone densitometer



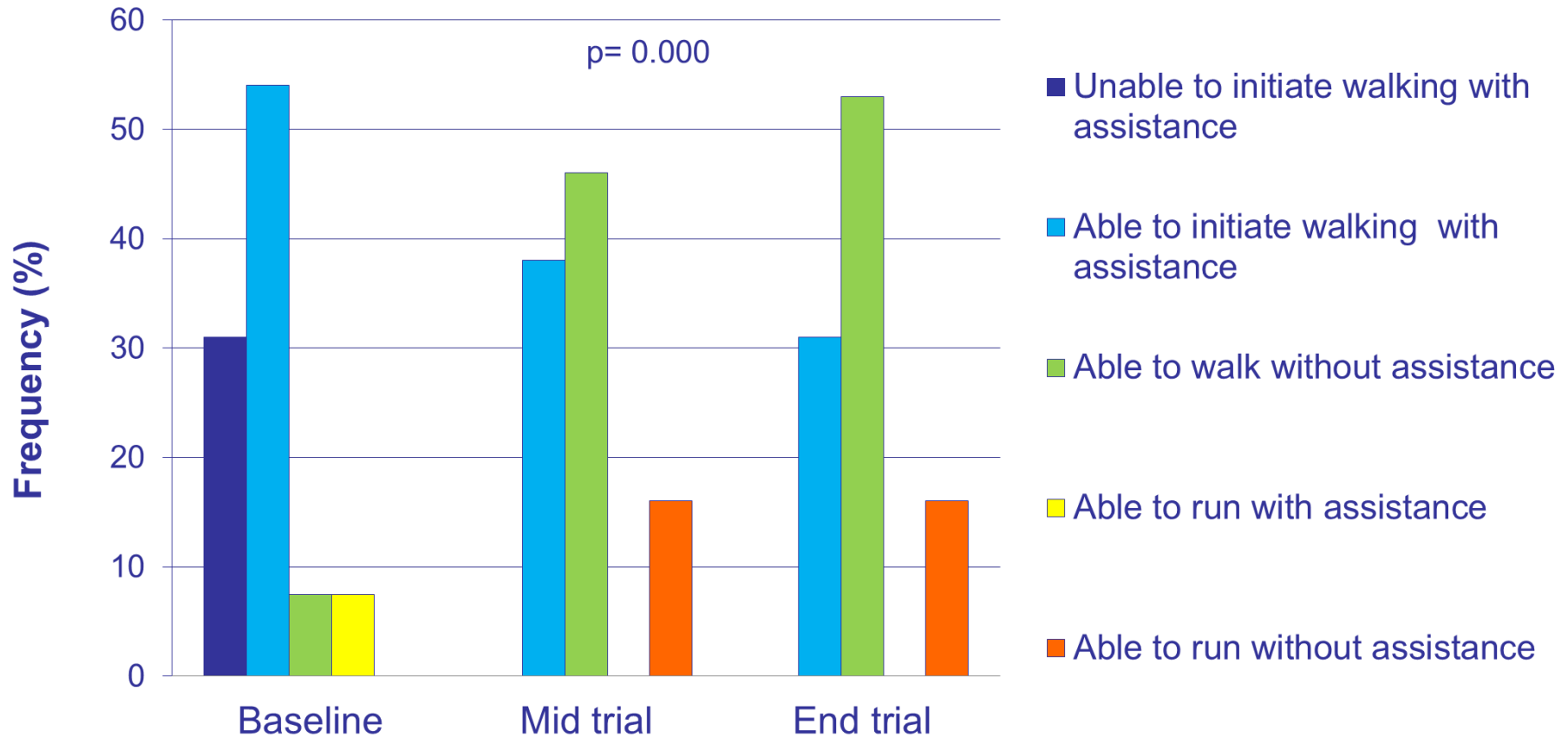
Participants

- Recruitment
 - Target n=12; actual n=15
 - Two specialist schools
- Participants
 - Age range 4-12 years (mean 8.4)
 - GMFCS levels (level IV = 10; level V = 5)
 - 7 boys, 8 girls



Results

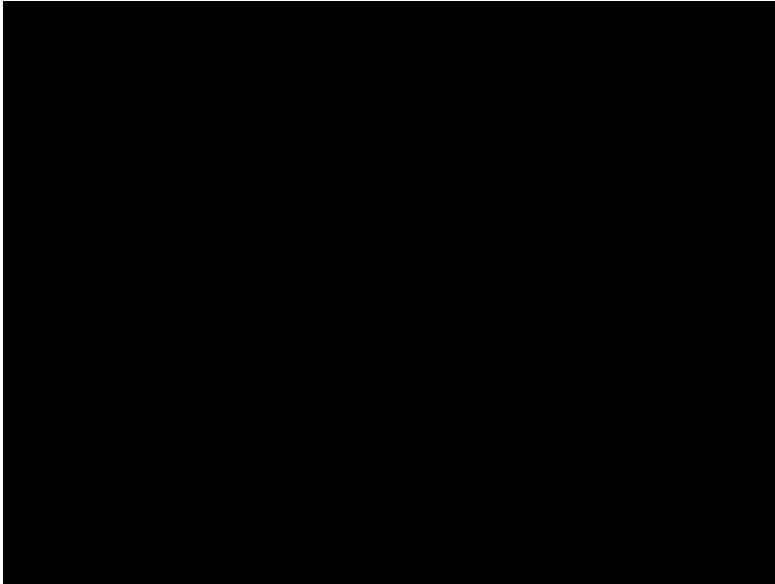
Ability to use the running bikes



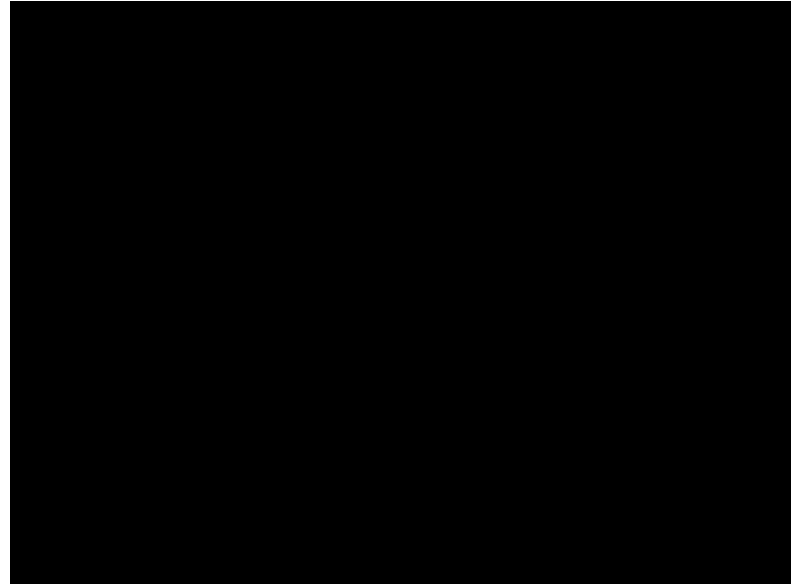
Running bike use

GMFCS level IV = Self mobility with limitations

Week 1



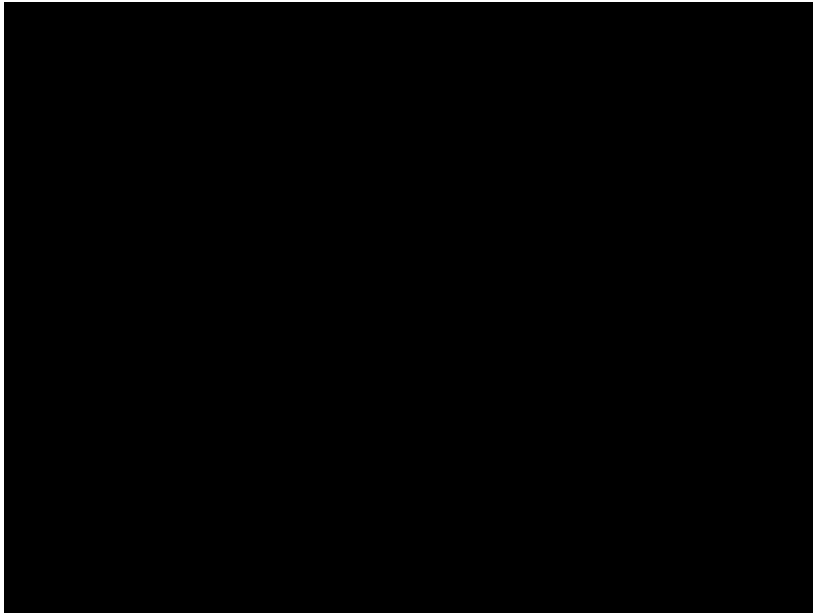
Week 12



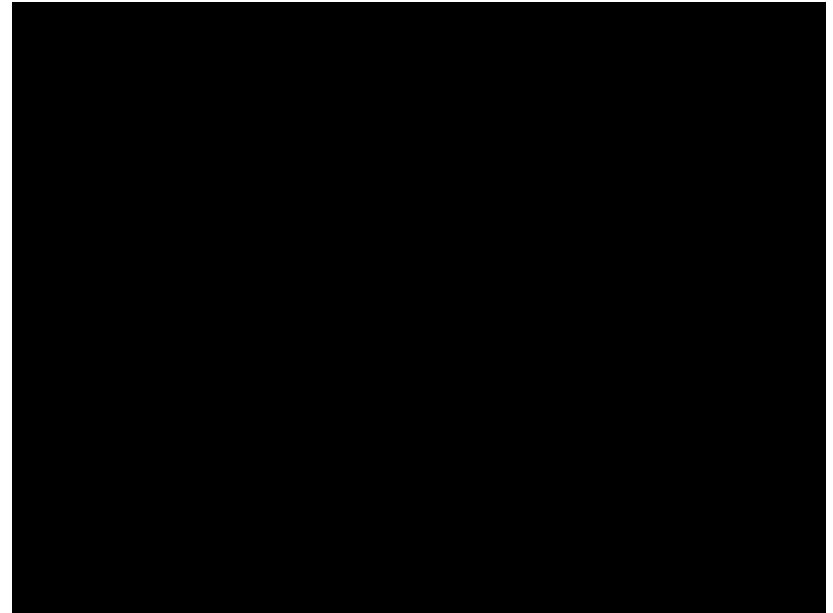
Running bike use

GMFCS level V = Transported in a wheelchair

Week 1



Week 12





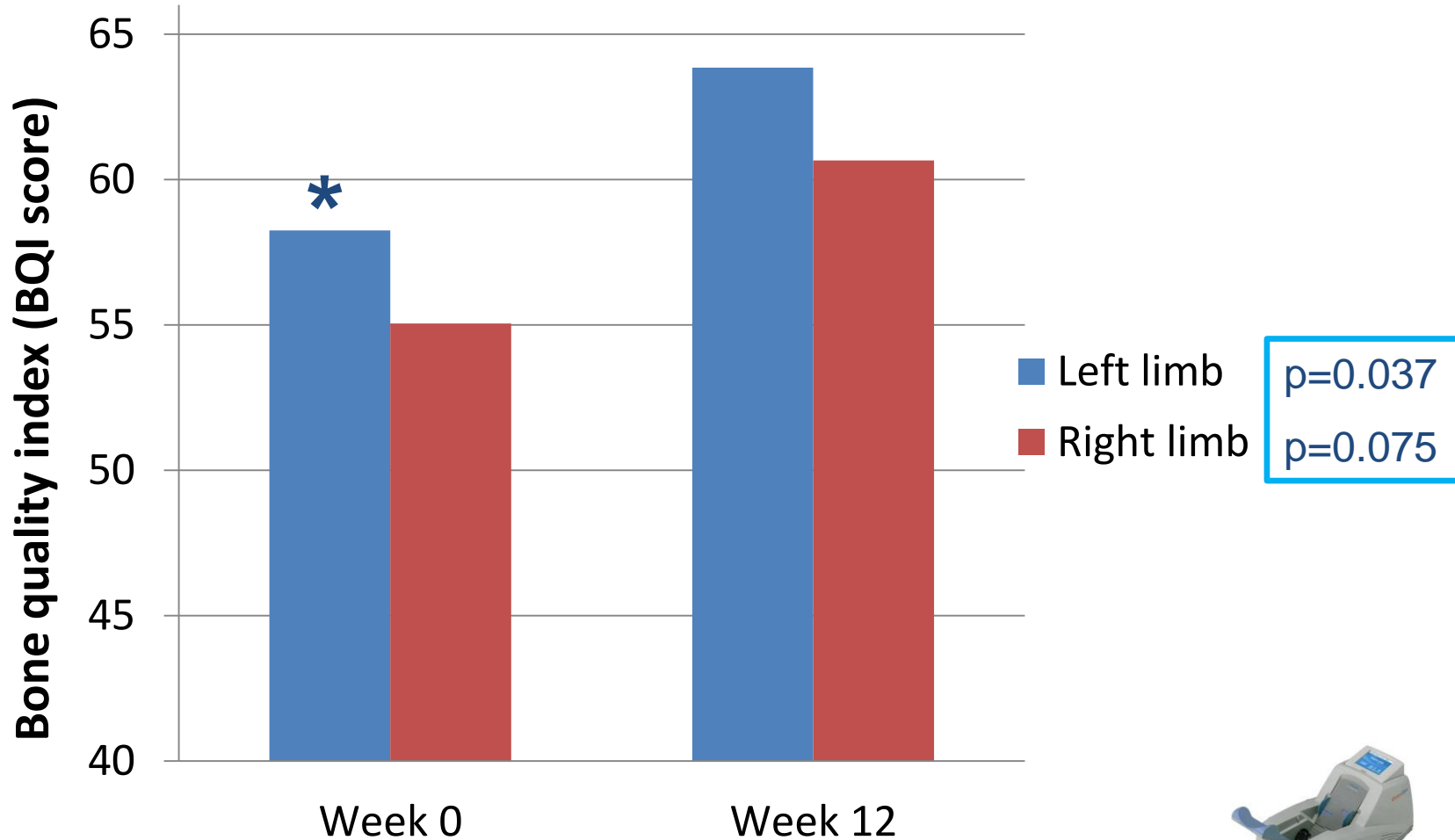
Qualitative feedback



- Physiotherapists
 - “They were really fun for the children”
 - “They could go really fast, and it was something they had never been able to do”
 - “For some it was the first time they have been able to completely move independently”
- Children
 - “It was really fun” “Happy” “Excited”
 - “I got hot!”

Results

Ultrasound bone data





Results

- Standing ability (GMFM-88D)

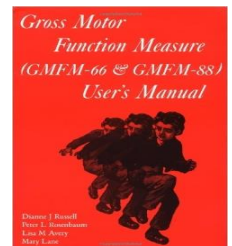
13 tasks include:-

1. Stands - arms free for 3 seconds
2. Stands - holding onto large bench with one hand, lifts 1 foot for 3 seconds

Scoring for each task:-

(0 = does not initiate, 1 = initiates, 2 = partially completes, 3 = completes)

- Showed signs of improvement (non significant)
 - Number of tasks attempted increased





Discussion

- Running bikes are fun and exciting for non-ambulant children with cerebral palsy
- Twelve week running bike use demonstrated positive health benefits
- Further research required



This study was funded by Sparks, the children's medical research charity



RaceRunning: improving wellbeing in people with cerebral palsy.

Dawn Pickering, Physiotherapist, PhD student,
Cardiff University



Well Being

- World Health Organisation, 2014
- NICE guidelines 2013
- Feeling valued as a person- subjectively experienced, realising own potential.

Emotional-happy and confident

Psychological- autonomous, resilient

Social – good relationships

RaceRunning Dragons, Cardiff



Race-Running Sport in Movement

Join us at Wales' first Race-Running Club
Activity that's new, fun, friendly and has amazing benefits

WHAT'S COMING UP
Opportunities to join us with local fun, run and cycle events, national events and the annual international Race-Running Camp and Cup in Copenhagen

What is it?
Training to walk, run and race with the support of a three-wheeled frame

Who is it for?
Anyone who has difficulties with movement, balance and walking but is allowed to bear weight

When?
Friday night is Race-Running night - We meet 5-7pm (term-time only)

Where?
Cardiff International Sports Stadium
Leckwith Road, Cardiff CF11 8AZ

How much?
Under 16s £1.90 - Over 16s £3.80
(includes track fees for use as of May 2015)

Our Phone: 07803 770 962
Our Email: gabriela.todd@yahoo.co.uk

How to support us?
Each race-runner costs £1,600 - Can you help fund or make a donation?
We need volunteers to help out at our club each Friday and athletes to help train our members.
Can you help with transport to events?

"For years I've sat on the side-lines watching others take off. Now I can take off too!"
Race-runner Joe

"The world of race-running is a limitless prairie. It takes away disability, replacing it with ability. It made my dream a reality."
Race-runner Hannah

RACERUNNING DRAGONS
© Cardiff Race-Running Dragons



About our Club

Cardiff Race-Running Dragons - the first club of its kind to be set up in Wales - is about having fun and experiencing the joys of sport, whatever your ability.

With physiotherapists and volunteers on board to offer help and support - and friends and family cheering in the team spirit too - it's a great, all inclusive, all-year round activity.

Our small committee of 5-7 people includes parents and therapists and we are lucky to have help on club nights from Cardiff University's occupational and physiotherapy students as well as the support of Cardiff's Athletic Stadium.

Members are encouraged to achieve their potential and we offer those interested the chance to attend the Race-Running Camp and Cup in Copenhagen in the summer. We also hope to liaise with other Race-Running clubs in the UK and join up with them for sporting and social events.

We plan to put on a variety of social events throughout the year, including a Christmas party.

We are happy to offer try-out events to interested groups and to give talks to anyone who would like to know more about us and perhaps even sponsor us too.

cardiff caerdydd

THE CYCLES FOUNDATION

KITTY ALL SET UP AND READY TO GO

TEAM SPIRIT: CARDIFF DRAGONS WITH SOME OF THEIR SUPPORTERS ON CLUB NIGHT

RAINING CHAMPION: IMOBEN BEATS THE WEATHER IN STYLE

CAMERA AND ANTHONY'S READY FOR THE ACTION

KITTY TAKES OFF

FINISH LINE

2 3 4 5 6 7

Moondance foundation- Cardiff Club -8 RaceRunners



Gabriela Todd



gabriela.todd@yahoo.co.uk

Racing



Community activity

Butetown Mile (@butetownmile)

1-mile run along Bute Street, Cardiff. Mostly straight, flat course with an elite entry and end for fun run.

Cardiff

[facebook.com/budetownmile?r...](https://www.facebook.com/budetownmile?r...)

TWEETS 127 FOLLOWING 140 FOLLOWERS 96 LIKES 53

Tweets Tweets & replies Photos & videos

Butetown Mile Retweeted

Aled Edwards @alededwardscym · Oct 5
Completed 3 races for @CdfTrinity - 100k @RaceToTheStones @butetownmile and @cardiffhalf buff.ly/1N9vRco

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18:03 23/11/2015

- *'I was introduced to a cerebral palsy specific sport called RaceRunning...it was just so freeing....it was just amazing!..... My activities were very short and staggered, I would never really raise my heart rate or get into an easy motor pattern. Gravity and my CP is what made my walking pattern so disjointed- the need to stay upright against gravity with muscles which co-contract at the faintest hint that I might fall. So at first the RaceRunner gave me the experience of what walking must be like without cerebral palsy- using motor patterns which come naturally and easily.....*



*....So it's so beautiful on the track, fresh air, you get to obviously run on the RaceRunner ...and you can switch off that part of your brain. I think motor function just uses more - because we've got less maybe - we've got damaged brains so the bits that are alive are working 100 fold more than they're meant to, it might be the fact that somehow they can switch off and you can start thinking. **What I can't do is think coherently when I walk, but I can when I Race Run...***



Carry over into other activities

...it created new abilities within me not necessarily physical...I had more self confidence and more ability to deal with stressful moments in my life...I actually applied for the student president of the faculty...I was so much more happy within myself...

Race Running is safe, you do need padded shorts and a padded saddle....you don't have to concentrate you just see the world go by.... it enabled me to stop hiding what I can't do and say look at what I can do!.....

Race Running- parental view



'We have found that Imogen's enthusiasm for physical activities like Race Running has enabled me and my husband to get fitter, it also helps her to sleep better.'

'Hands on' time!

- Demo / how to set up the RR's for different users
- Have a go!







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