

Are boys with severe haemophilia as physically active as the normal population?

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Physical Activity and Haemophilia

- ◆ Sport and physical activity are now considered to be essential.
- ◆ Actively encouraged.
- ◆ Increase participation in sport and leisure activities.



Importance of Physical Activity

- ◆ Tiktinsky et al (1998)
 - ◆ Showed regular exercise can reduce bleeding episodes
- ◆ Hilberg et al (2003)
 - ◆ Increased strength and proprioception without an increase in bleeding



Importance of Physical Activity

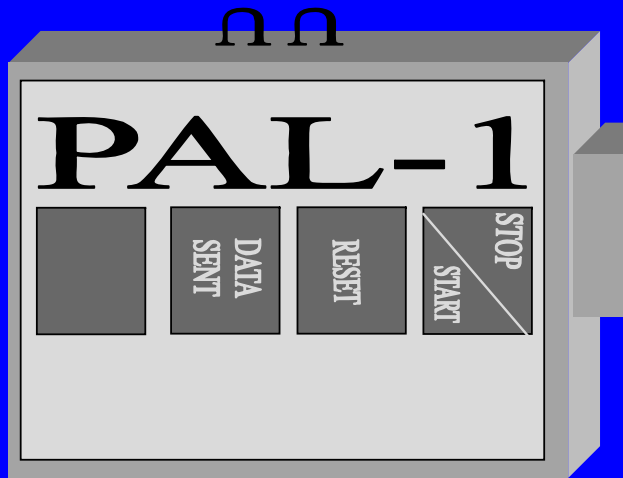
- ◆ Barnes et al (2004)
- ◆ Reduced BMD compared with controls
- ◆ Recurrent joint bleeds enforce extended periods of non-weight bearing and reduced physical activity.
- ◆ Also type of activity encouraged was not high intensity weight-bearing activity.



Measurement of Physical Activity

- ◆ No quantitative measurements.
- ◆ Various authors have attempted to investigate physical activity.
 - ◆ Schoenmakers et al (2001) and Heijnen et al (2001) found no difference in physical activity.
 - ◆ However Falk et al (2000) found a significant difference in activity.
- ◆ Results were derived from questionnaires.
- ◆ Sallis (1991) raises doubts over validity of data obtained about physical activity from questionnaires.

Measurement of Physical Activity



- ◆ PAL-1 - a remote activity monitor that records uptime (time spent in the upright position).
- ◆ Uptime
 - ◆ Indication of WB activity
 - ◆ Can be used as measure of physical activity. (Sanders, 1983)
- ◆ Newer version of Uptimer

Measurement of Physical Activity

- ◆ Eldridge et al (2003)
- ◆ Investigated 529 normally developing children.
- ◆ Established a normative database for children in Victoria.
- ◆ Further studies demonstrated that the Uptimer and PAL-1 were valid measurement tools for children in these diverse clinical settings.

Uptime and Haemophilia

- ◆ Study aims
 - ◆ Measure uptime in boys with severe haemophilia
 - ◆ Compare it with uptime in unaffected children

Uptime and Haemophilia

◆ Subjects

- ◆ Severe haemophilia
- ◆ Patients of Henry Ekert Haemophilia Treatment Centre (HEHTC).
- ◆ Age range 6-16 years
- ◆ All but two on prophylaxis
- ◆ Exclusion criteria - associated neurological problem.

Uptime and Haemophilia

- ◆ Method
- ◆ PAL-1 placed on lateral right thigh, secured with clear adhesive sheets.
- ◆ PAL-1 has three tilt switches that sense when device is upright.
- ◆ Upright position = uptime
- ◆ Sitting or lying = downtime



Uptime and Haemophilia

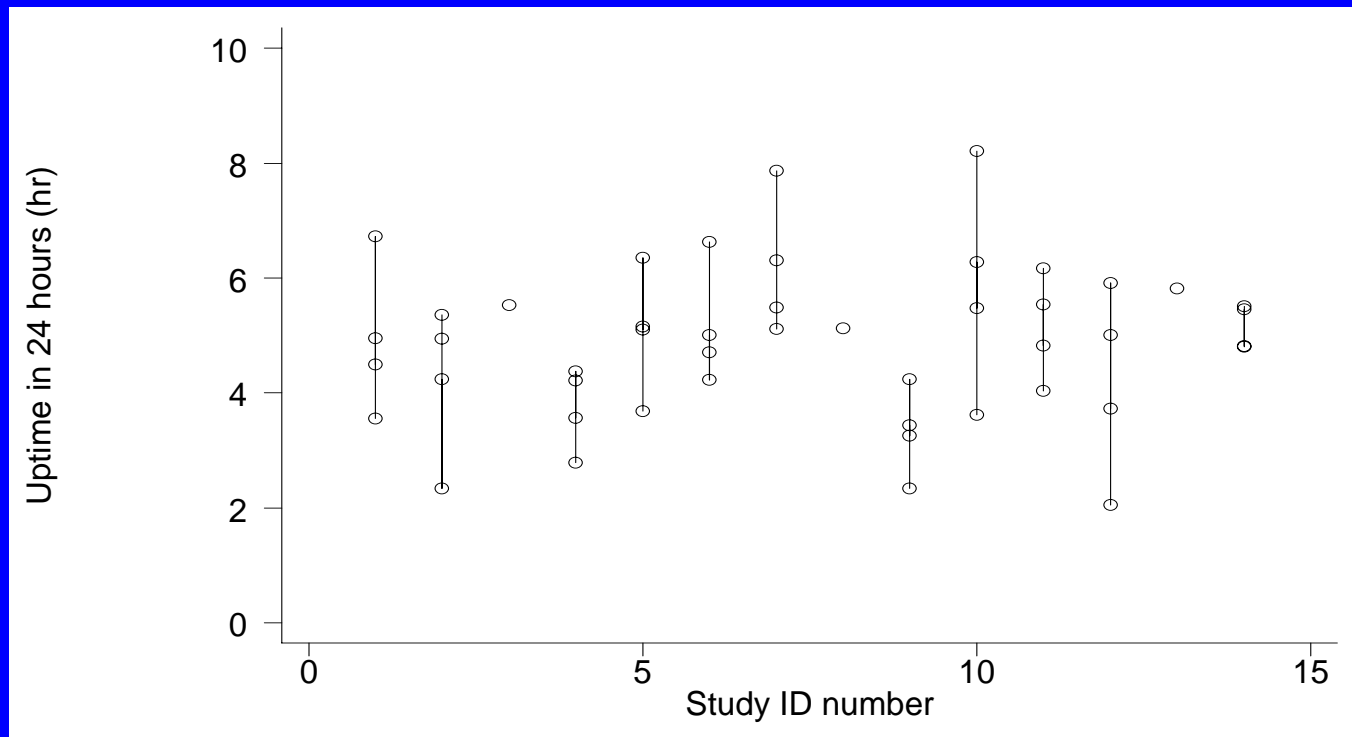
- ◆ PAL-1 worn for four days.
- ◆ Removed at home and returned to hospital via family or courier.
- ◆ Data downloaded for analysis.
- ◆ Data is in hours and minutes and analysed as four separate 24-hour periods.
- ◆ Uptime was summarised as a mean and standard deviation of hours of uptime in 24 hours.

Uptime and Haemophilia - Results

- ◆ Seventeen subjects wore PAL-1
- ◆ No inhibitors
- ◆ Three subjects data unable to be used
- ◆ Three subjects had only one day recorded.
- ◆ The other eleven boys wore the monitor for four full days.

Uptime and Haemophilia

◆ 47 complete 24-hour periods



Uptime and Haemophilia - Results

	Haemophilia Boys	Healthy Males (Eldridge, 2003a)
Mean Uptime/24 hours	4.9h	5.3h
SD/24 hours	1.3h	1.5h
Range	2.0 – 8.2h	1.5 – 10.3h

Uptime and Haemophilia - Results

	Haemophilia Boys	Healthy Subjects (Eldridge 2003c)
Within child variability (SD)	1.2h	1.1h
Between child variability (SD)	0.6h	0.8h

Uptime and Haemophilia - Discussion

- ◆ Presumed activity levels were comparable
- ◆ Demonstrates haemophilia boys have similar levels of activity as their peers
- ◆ Results indicate, on average 24 minutes difference



Uptime and Haemophilia - Discussion

- ◆ Limitation – small sample size
- ◆ Novel approach to assessing physical activity levels
- ◆ Uptime provides accurate data
- ◆ Information may lead to change in child's lifestyle and improvement in health status
- ◆ Increase risk of reduction in BMD (Barnes 2004)
 - ◆ Imperative boys participate in appropriate activities at appropriate level

Uptime and Haemophilia

- ◆ Acknowledgments
 - ◆ Small clinical grant from the Murdoch Children's Research Institute
 - ◆ My co-authors