

# Comparison of self- and parent-estimated health-related quality of life with cardiopulmonary exercise testing in Croatian children and adolescents with congenital heart disease

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**INTRODUCTION:** In adult medicine it's established that exercise tests and health-related quality of life (HRQOL) instruments should be used together to get an appropriate overview of the health status of patient with congenital heart disease (CHD). Information on that in children is lacking.

**AIMS:** Study analyses the self- and parent-reported HRQOL among patients with CHD, treated in tertiary pediatric cardiology care center, with the aim to compare perception of HRQOL between patients and their parents, and both with cardiopulmonary exercise testing (CPET) parameter - peak oxygen uptake ( $pVO_2$ ) - as the best represent of exercise capacity and cardiopulmonary fitness.

**PARTICIPANTS AND METHODS:** A cross-sectional, single-centre, observational study was performed on 63 patients aged 8 to 18 years (40 M, 23 F), with various CHD, under routine follow-up. A significant proportion of patients had previous Fontan procedure (32%). Patients and their parents completed a HRQOL questionnaire - PCQLI<sup>®</sup>. We analysed answers on the general health perception item, given at 5-point Likert scale. Afterwards, CPET with Bruce treadmill protocol was performed under same conditions, conducted by one of the authors. Descriptive and inferential statistics were used for data analysis, including calculation of Spearman's rank correlation coefficients for the comparison of HRQOL and  $pVO_2$ .

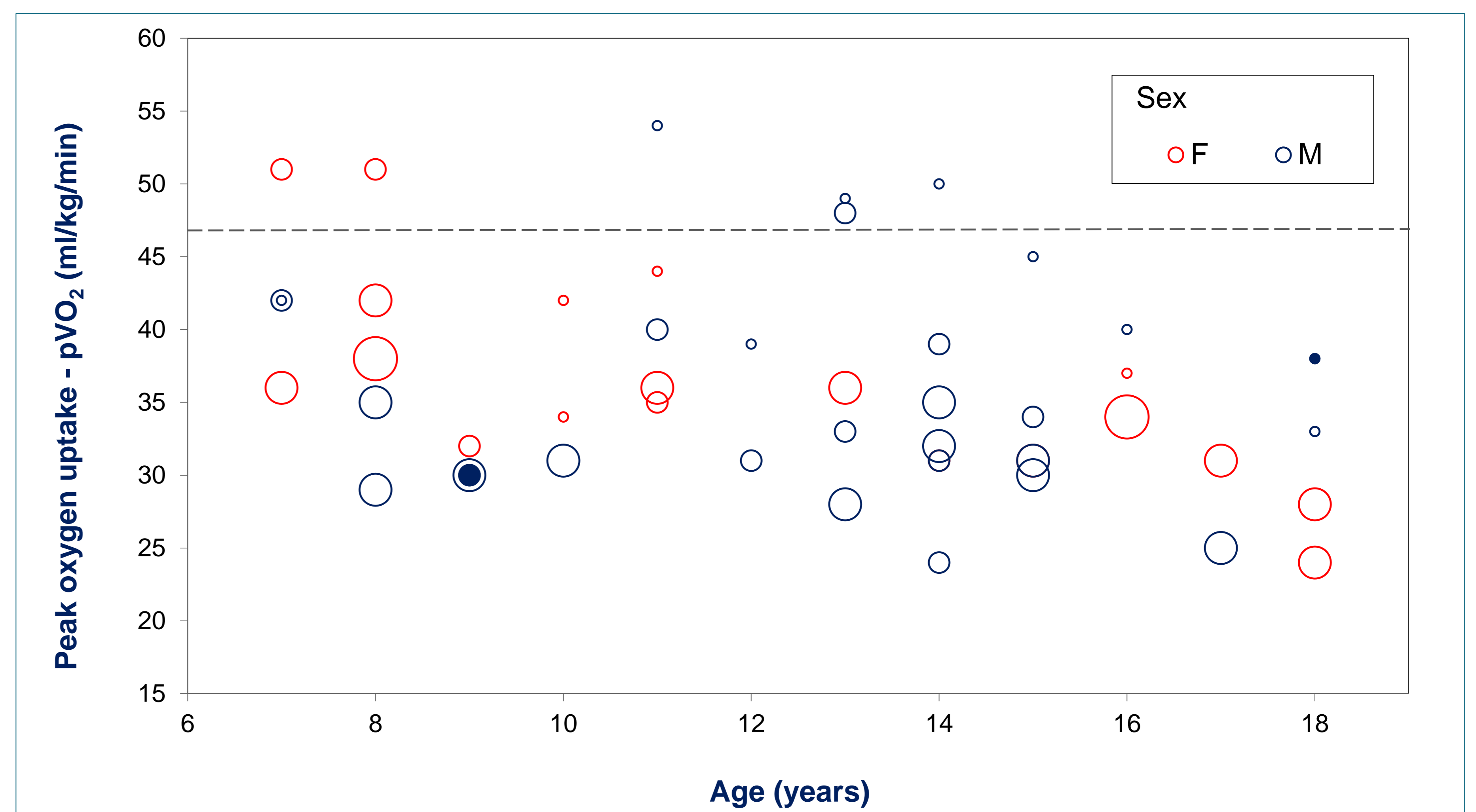
**Table 1.** Matching of self- and parent-estimated HRQOL (health perception: 1 - excellent, 2 - very good, 3 - good, 4 - fair, 5 - poor).

Patients answers	Parents answers					Total
	1	2	3	4	5	
1	10	5	1	1		17
2	2	14	3	1		20
3		5	15	1		21
4		1	1	1		3
5						
<b>Total</b>	<b>12</b>	<b>25</b>	<b>20</b>	<b>4</b>		<b>61</b>

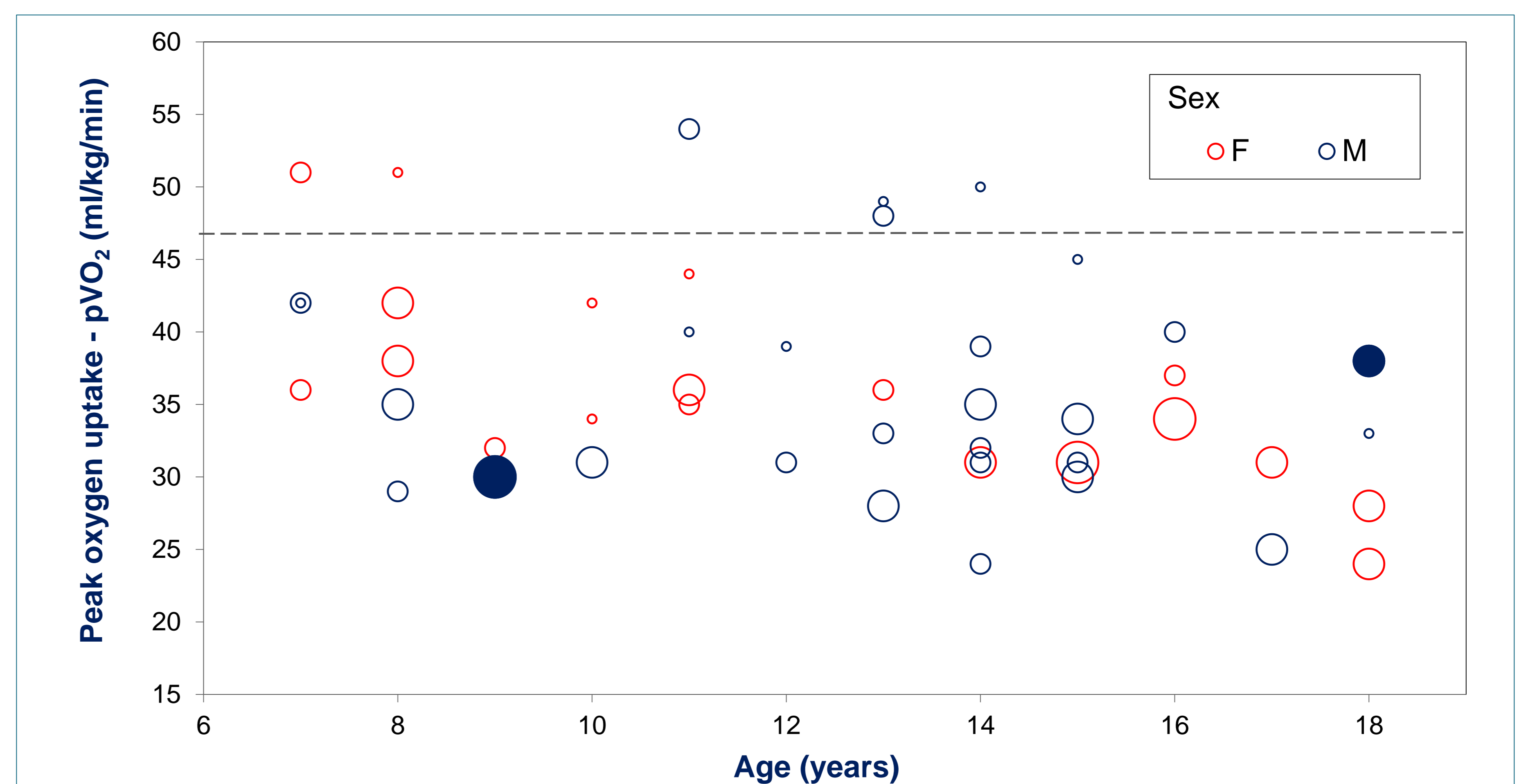
**RESULTS:** To describe the study group, mean  $pVO_2$  were compared with reference values of healthy pediatric population, local and from the literature; by Student's t-test, patients value was significantly lower ( $p < 0.01$ ) for both gender.

Excellent matching of self- and parent-estimated health-related quality of life was found: in 65% identical, in 20% parental perception was worse, while in 15% parents underestimate childrens' impairments (Table 1).

Peak oxygen uptake correlated significantly with the general health perception - of patients ( $r = 0.608$ ,  $p < 0.05$ ), and of their parents ( $r = 0.610$ ,  $p < 0.05$ ).



**Figure 1.** Comparison of **self reported QOL** with peak oxygen uptake from a CPET; dashed line represents normal  $pVO_2$  value; bubble size is inversely proportional with the general health perception (bigger bubble means worse general health perception).



**Figure 2.** Comparison of **parent reported QOL** with peak oxygen uptake from a CPET; dashed line represents normal  $pVO_2$  value; bubble size is inversely proportional with the general health perception (bigger bubble means worse general health perception).

**CONCLUSIONS:** In general, our patients had reduced exercise capacity. Peak oxygen uptake was in good correlation with the perception of health, made by patients and by their parents: better perception of health mainly means better  $pVO_2$ . But, in case of mismatching, fatal outcomes can happen. So, complementary usage of these two methods should be helpful in advising patients on activities of daily life, sports participation, and choice of occupation.