AEPC Psychosocial Care from Fetus to Adult
Working Group Biannual Meeting
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Congenital Heart Diseases and Sports

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Children have an elementary need for motor activity

The children's perceptual and motor experience not only determines their **physical and motor development** but also decisively influences their **emotional, psycho-social, and cognitive development**

Deficiency in this field might affect the children's entire personal development in a negative way

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Physical inactivity in childhood is abnormal!

- regardless of whether it is due to physical, emotional, psycho-social or cognitive factors

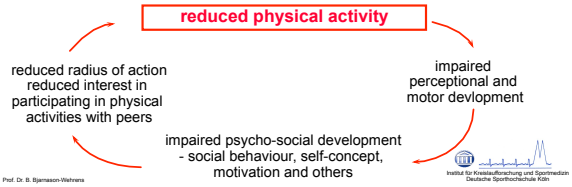
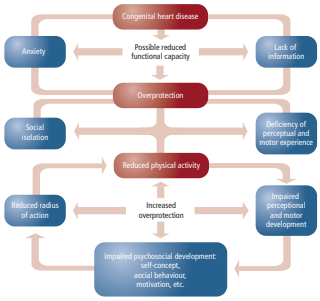


Figure 1: Conditional Network of Possible Causes and Effects of Physical Inactivity in Children with Heart Diseases – Vicious Circle of Reduced Physical Activity



Physical activity patterns of children after neonatal arterial switch operation. Massin et al. Ann Thorac Surg 2006;81:665-70.

Group A) 52 children and adolescents (aged 7-14 years) **after neonatal arterial switch operation**
Group B) 35 children with repaired atrial or venticular septal defect
Group C) 124 age-matched healthy children

Assessment: 24-hour continuous heart rate monitoring using the percentage of heart rate reserve to measure the amount of physical activity

Results:
The CHD group was significantly less physically active than healthy peers

- 19% (Group A) and 31% (Group B) of the CHD patients engaged in more than 30 minutes a day of moderate activity compared to 57% of the healthy peers (Group C) (p=0.004)
- 27% (Group A) and 34% (Group B) of the CHD patients engaged in more than 20 minutes a day of vigorous activity compared to 47% of the healthy peers (Group C) (p=0.020)

Physical activity levels in children and adolescents are reduced after the Fontan procedure, independent of exercise capacity, and are associated with lower perceived general health. McCrindle et al. Arch Dis Child 2007 ;92:509-14.

147 patients, mean age 11.6 years (7-18 years) at a median of 8.1 years after the Fontan procedure
Assessment: a.o. questionnaire of self reported physical activity, measurement of habitual physical activity using uni-axial accelerometer and others

Results:
- ✓80% participated in gym class at school
- ✓33% reported they were less active than their friends

The measured time spent in moderate and vigorous activity was markedly below normal at all ages
- ✓38% of the patients achieved the current physical activity recommendations for children and adolescents

Objectively measured physical activity levels was not significantly related to self-reported activity levels .

Children should do at least 60 minutes of physical activity daily. (http//www.cdc.gov/physicalactivit</everyone/guidelines/children. html)

Moderate to vigorous physical activity ≥ 90 min/d are recommended for optimal health.

Sedentary lifestyles immediately impact peer socialization and hinder motor skill development, which may lead to decreased activity self-efficacy and increase the risk of sedentary lifestyle morbidities (obesity, diabetes and atherosclerosis)

Effect of activity restriction owing to heart disease on obesity.
Stefan et al. Arch Pediatr Adolesc Med 2005;159:477-81.

Exercise-intolerant and activity restricted children experienced larger increases in the absolute body mass index (BMI) and the BMI percentile than children with neither exercise intolerance nor activity restrictions

110 CHD patients - follow up for 8.4 years
(aged 3.9 ± 2.5 baseline and 12.7 ± 3.1 at follow up)

activity restriction was the strongest predictor of the risk of being **overweight** (RR, 2.60; 95% CI, 1.34-3.54) and **obese** (RR, 4.08; 95% CI, 1.42-7.38) at follow up

Factors associated with the physical activity level of children who have the Fontan procedure
Longmuir et al. Am Heart J 161(2); 2011:411-417

Children with complex heart defects are sedentary, with activity level unrelated to exercise capacity.

Aim: to identify factors associated with physical activity level for children who have the Fontan procedure

Subjects: 64 children (25 female, 5-11 years) after Fontan.

Measurements: weekly minutes of moderate-to-vigorous physical activity, cardiac status, resting/exercise cardiopulmonary capacity, gross motor skills, health related endurance/strength/body composition and parent/child activity perception.

Factors associated with the physical activity level of children who have the Fontan procedure
Longmuir et al. Am Heart J 161(2); 2011:411-417

Main results:
Participants performed 361 ± 137 min/week of moderate-to-vigorous physical activity
Increased activity was related to:
- antithrombotic medication use (86 min/week),
- **higher weekly outdoor time (0.7 minute per outside minute)**
- lower family income (13 min/ week per $ 10.000),
- **higher parent rating of child´s activity relative to peers**

Decreased activity was related to:
- winter season (-84 min/week)
- history of arrhythmia (-96 min/week)
- **greater child's confidence in own ability to be active (-113 min/week)**

Factors associated with the physical activity level of children who have the Fontan procedure
Longmuir et al. Am Heart J 161(2); 2011:411-417

Conclusion:
Physical activity after the Fontan procedure is primarily associated with factors unrelated to cardiac status.
Interventions that impact these modifiable factors would be expected to enable these children to achieve the recommended activity levels associated with optimal health.

Development of motor abilities in children with congenital heart disease compared to heathy peers

Impaired Coordination in Children with Congenital Heart Disease – Only hardly to be Explained by medical Causes?
Unverdorben et al.: Herz/Kreisl 29 (1997), 181-184

Gross and fine motor development is impaired in children with cyanotic congenital heart disease.
Stieh et al. Neuropediatrics 30 (1999), 77-82

Efficiency of psychomotor training of children with (partly-) corrected congenital heart disease
Dordel et al. Deutsche Zeitschrift für Sportmedizin 50 (1999), 5-11.

Impaired motor competence in school-aged children with complex congenital heart disease.
Holm et al. Arch Pediatr Adolesc Med 2007;161:945-50

Motor Development in Children with Congenital Heart Diseases Compared to Healthy Peers
Bjarnason-Wehrens et al. Cardiology in the Young (2007);17 (5): 487-498

Impaired motor competence in school-aged children with complex congenital heart disease.
Holm et al. Arch Pediatr Adolesc Med 2007;161:945-50.

Study Group
120 children (aged 7 to 12 years) who had undergone a surgical repair with multiple and complex correction within the first year of life were compared with 387 healthy school children at same age.

Assessment: The Movement ABC for testing motor skills, isokinetic strength measurement for knee extension and flexion and hand dynamometer for isomeric grip strength

Impaired motor competence in school-aged children with complex congenital heart disease.
Holm et al. Arch Pediatr Adolesc Med 2007;161:945-50.

Results:
Children with CHD scored significantly worse for manual dexterity, ball skills, static and dynamic balance, grip strength and quadriceps muscle strength.

Compared with the healthy peers, children with complex congenital heart diseases had **5.8-fold** (95% confidence interval, 3.8-8.8) **risk of having any degree of impaired motor competence.**

The risk to have severe motor disturbances was 11-fold (95% confidence interval, 5.4-22.5).

Motor Development in Children with Congenital Heart Diseases
Compared to Healthy Peers
Bjarnason-Wehrens et al. Cardiology in the Young (2007);17 (5): 487-498

Survey of children with congenital heart diseases

Children and adolescents with congenital heart diseases:
n = 194
106 boys, 88 girls,
mean age 10.0 ± 2.7 years,
(Median: 10; Range: 5 to <15 years)

Control group (healthy schoolchildren):
n = 455
220 boys, 235 girls,
mean age 9.6 ± 2.17 years,
(Median: 9; Range: 7 to <15 years)

The primary cardiac diagnosis present in the CHD (* also in combination with other diagnosis)

Cardiac diagnosis	n	%
ventricular septal defect (VSD)	47*	24.2
tetralogy of Fallot (ToF)	28	14.4
coarctation of the aorta (CoA)	23*	11.9
atrial septal defect. (ASD II)	19*	9.8
aortic stenosis (AS)	16*	8.2
transposition of the great arteries (TGA)	14	7.2
pulmonary stenosis (PS)	12*	6.2
complex lesions / single ventricle physiology	10	5.1
arrhythmia	9*	4.6
persistent ductus arteriosus (PAD)	8*	4.1
aortic insufficiency (AI)	7*	3.6
mitral insufficiency (MI)	7*	3.6
persistent foramen ovale (PFO)	3*	1.5
Ebstein's anomaly	3	1.5
transposition of pulmonary veins	2	1.0
long Qt syndrom (LQTS)	2*	1.0
other diagnosis	8	4.1

Bjarnason-Wehrens B, et al. Cardiology in the Young (2007) 17 (5): 487-498

Motor Development in Children with Congenital Heart Diseases
Compared to Healthy Peers
Bjarnason-Wehrens et al. Cardiology in the Young (2007);17 (5): 487-498

All children with syndromes, disabilities or co-morbidities with consequences for their motor abilities were excluded

This was also true for all children with obvious mental retardation and other risk factors than CHD for an abnormal neurological development (such as perinatally acquired cerebral lesions, auditory and visual problems etc.)

The body-coordination-test for children (KTK)

Schilling F. Körperkoordinationstest für Kinder. KTK Manual. Weinheim: 1974

Balancing backwards
MQ 1

Monopedal jumping
MQ 2

Sidewise jumping
MQ 3

Sidewise moving on boards
MQ 4

The body-coordination-test for children (KTK)

Schilling F. Körperkoordinationstest für Kinder. KTK Manual. Weinheim: 1974

Motor Quotient (MQ)	Classification
131-145	high motor development
116-130	good motor development
86-115	normal motor development
71-85	moderate motor disturbances
56-70	severe motor disturbances
< 56	below classification level

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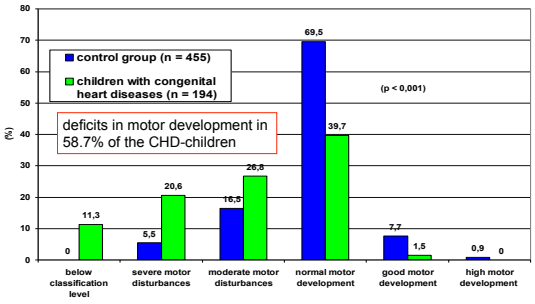

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Classification according to current cardiac situation and postoperative clinical findings.
(**Group: A no or mild RS**, *Group B: significant RS*).

Group I: patients after heart surgical/catheter interventional operations	
1. no residual sequelae (complete correction)	10
2. with mild residual sequelae	53
3. with significant residual sequelae	63
4. patients with complex heart defects after palliative interventions	7
a) such as the Fontan operation or the Mustard operation for TGA, where separation of systemic and pulmonary circulation has been achieved	5
b) patients in whom the two circulatory systems have not been separated (e.g. aortopulmonary shunt operation)	2
Group II: patients with heart defects not requiring operation	
1. shunt lesions with insignificant left to right-shunt such as small atrial or ventricular septal defect.	21
2. insignificant valvular defects/anomalies such as congenital bicuspid aortic valve	19
3. insignificant arrythmia/ ECG-abnormality	5
4. insignificant myocardial changes	3
***Group V:** patients with complex arrythmia*	3

Bjarnason-Wehrens et al Cardiology in the Young (2007); 17 (5): 487-498

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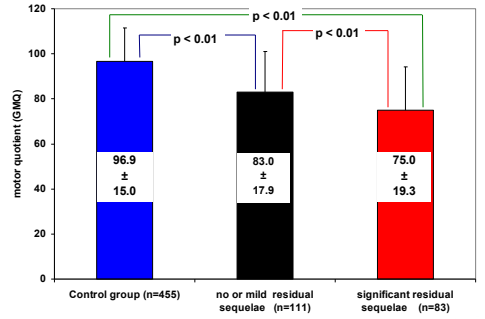

Bjarnason-Wehrens et al. Cardiology in the Young (2007); 17 (5): 487-498

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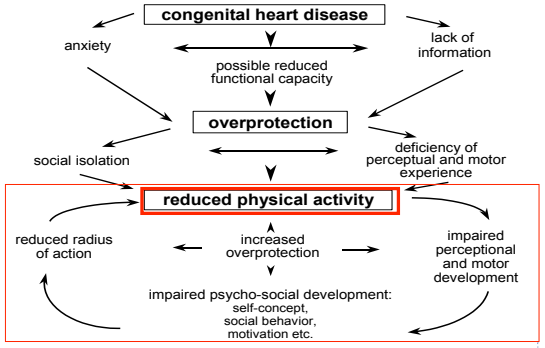

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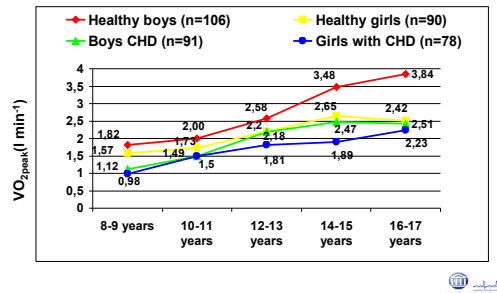
A comparison of VO_2(peak) between patients with congenital heart disease and healthy subjects, all aged 8-17 years.

Fredriksen et al. Eur J Appl Physiol Occup Physiol 80 (1999),409-16



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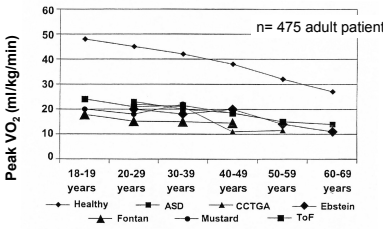
Aerobic capacity in adults with various congenital heart diseases.
Fredriksen et al. Am J Cardiol 2001;87:310-304



Reduced exercise capacity (25%-50%) in all groups but with great variance between diagnosis groups (VO2peak range 6 to 45 ml/kg/min) showing the lowest values within in the Fontan group

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Exercise intolerance in adult congenital heart disease: comparative severity, correlates, and prognostic implication.
Diller et al. Circulation 2005;112:828-35

Study population: 335 adult patients (mean age 33 ±13 years) 55% males, with wide spectrum of congenital heart diseases

Assessment: cardiopulmonary exercise testing

Follow up: median follow-up time 304 days; (range 17-580 days) (endpoints: hospitalisation or death)

- cardiopulmonary exercise capacity (peak VO_2 ml/kg/min)
- prognostic value of cardiopulmonary exercise capacity (peak VO2 ml/kg/min)

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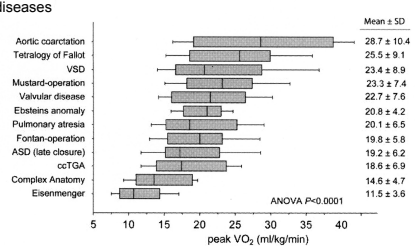
Study group: 335 adult patients (mean age 33 ±13 years) with wide spectrum of congenital heart diseases

peak VO_2 (ml/kg/min)
21.7 ± 8.5
in adult patients

compared to
45.1 ± 8.
in healthy subjects

(p<0.0001)



Distribution of peak VO2 ml/kg/min in different diagnosis groups

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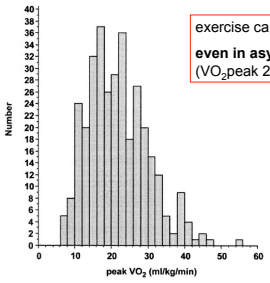

exercise capacity was diminished in all patients,

even in asymptomatic patients (NYHA-class I) (VO_2peak 26.1 ± 8.2 ml/kg/min)

Distribution of peak VO_2 ml/kg/min in asymptomatic adult patients (NYHA-class I).

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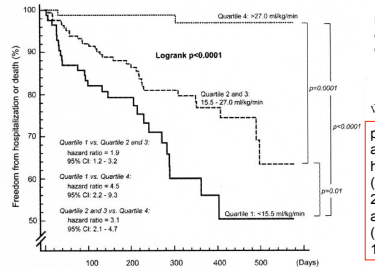

Kaplan-Meier plots for combined end points of hospitalisation or death (event-free survival).

peak VO2 < 15.5 ml/kg/min is associated with higher risk of hospitalisation or death (hazard ratio 2.9; 95% CI 2.2-7.4 p<0.0001) and death alone (hazard ratio 5.6; 95% CI 1.4-31.2 p<0.02).

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Exercise prescription in adults with congenital heart disease: a long way to go.
Swan & Hillis, Heart 2000 83:685-7

Study group: 99 adults with wide spectrum of congenital heart diseases (57 male, mean age 25.6 years)

Assessment: anonymous self assessment questionnaire

In adult patients with CHD safety, efficiency as well as potential health benefits of physical activity and exercise training are usually not addressed by the physicians

- 71% reported this topic had never been raised spontaneously by their physicians
- 19% reported they had been encouraged to be more physically active
- 11% stated that they had been told to have no exercise limitation due to the cardiac disease – but more commonly patients were told which kind of exercises were prohibited

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Physical activity levels in adults with congenital heart disease.

Dua et al. Eur J Cardiovasc Prev Rehabil 2007;14:287-93.

Study group: 61 adults with wide spectrum of congenital heart diseases (36 male; 31.7 ± 10.9 years)
physical activity level assessed using accelerometer over one week

Results:

The range of physical activity was seen between normal and severely limited, declining with increasing severity of the disease

only 23% of the asymptomatic patients (NYHA-class I) engaged in more than 30 minutes a day of moderate activity

NYHA-class II 15% (p< 0.005) NYHA-class III 0% (p<0.001)

Most of the patients were willing to participate in physical activity and exercise but were unsure about the safety and the benefits of such activities

Advises on physical activity and sports should be included in clinic consultations

Exercise training in adults with congenital heart disease: Feasibility and benefits

Dua et al. Int J of Cardiology 138 (2010), 196-205

Study group: Sixty-one adults (36 males; mean age 31.7+/−10.9 yrs) divided into 3 groups according to NYHA class.
Fifty patients completed the intervention and all pre-post assessments. Group I (n = 21; 13 males), Group II (n = 16; 10 males), Group III (n = 13, 10 males).

Exercise training (home based walking 5/7 days) for 10 weeks

Assessment: quality of life and physical activity questionnaires; treadmill exercise test; physical activity assessment with accelerometers [Caltrac® and Actigraph®]; Intital and after 10 weeks

Results:
In all groups after exercise training in all groups significant increase in

- ✓ quality of life–scores
- ✓ physical activity questionnaires-scores
- ✓ treadmill test duration
- ✓ physical activity levels assessed by the Caltrac® and the Actigraph® in all groups.

Conclusions: A simple physical activity intervention like regular walking is feasible, safe and significantly increases the exercise capacity of adult patients at all stages of congenital heart disease. It is also helpful in improving the quality of life by improving physical self-perception, satisfaction with life, physical activity levels and general health.

These results emphasise the importance of encouraging children and adolescents and adults with congenital heart diseases to engage more in physical activity and exercise training in order to avoid sedentary behaviour in adulthood and prevent atherosclerotic cardiovascular disease.

Recommendations for physical activity in congenital heart disease

1. Mitchell et.al. Sixteenth Bethesda Conference: Cardiovascular abnormalities in the athlete: Recommendations regarding eligibility for competition. JACC 1985; 6:29-30.
2. Kaminer SJ, Hixon RL, Strong WB. Evaluation and recommendations for participation in athletics for children with heart disease. *Curr Opin Pediatr* 1995;**7**:595-600.
3. Goldberg B. Sports and exercise for children with chronic health conditions. Guidelines for participation from leading pediatric authorities. Champaign: Human Kinetics, 1995.
4. Graham et al. Task Force 2: congenital heart disease. J Am Coll Cardiol 2005; 45:1326-33.
5. Reybrouck T, Mertens L. Physical performance and physical activity in grown-up congenital heart disease. *EJCPR* 2005;12:498-502.
6. Picchio et al. Can a child who has been operated on for congenital heart disease participate in sport and in which kind of sport? *J Cardiovasc Med (Hagerstown)* 2006;7:234-
7. Hirth et al.. Recommendations for participation in competive and leisure sports in patients with congenital heart disease. A consensus document. *EJCPR* 2006;13:293-9.
8. Bjarnason-Wehrens et al. Cardiac Rehabilitation in Congenital Heart Disease. In: Perk et al. Cardiovascular Prevention and Rehabilitation. Springer; London; 2007 PP:
9. Schickendantz et al. Sport and Physical Activity in Children with Congenital Heart Disease. Dtsch Arztebl 2007;104(9): A563-9 (www.aerztebl.de)
10. Thaulow E & PM Fredriksen: Exercise and training in adults with congenital heart diseases. International Journal of Cardiology 97; 2004; 35-38
11. **Takken et al. Recommendations for physical activity, recreation sport, and exercise training in paediatric patients with congenital heart disease: a report from the Exercise, Basic& Translational Research Section of the European Association of Cardiovascular Prevention and Rehabilitation, the European Congenital Heart and Lung Exercise Group, and the Association for European Paediatric Cardiology. European Journal of Preventive Cardiology 19 (2011) 1034–1065**
12. **Schickendantz et al. Sporttauglichkeit bei Kindern mit angeborenen Herzfehlern. Monatsschr Kinderheilkd 2012 DOI 10.1007/s00112-012-2773-7**

Recommendations for physical activity in congenital heart disease

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2. Kaminer SJ, Hixon RL, Strong WB. Evaluation and recommendations for participation in athletics for children with

In general, children with CHD should be advised to comply with public health recommendations of daily participation in 60 min or more of moderate-to vigorous physical activity that is developmentally appropriate and enjoyable and involves a variety of activities.

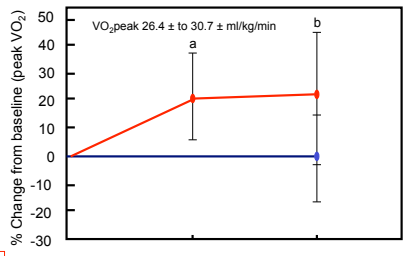
In keeping with these recommendations, all youth with CHD who fulfil the necessary requirements should have the opportunity to participate in physical activity and, if needed, take part in specially adapted programs of physical education.

11. Takken et al. Recommendations for physical activity, recreation sport, and exercise training in paediatric patients with congenital heart disease: a report from the Exercise, Basic& Translational Research Section of the European Association of Cardiovascular Prevention and Rehabilitation, the European Congenital Heart and Lung Exercise Group, and the Association for European Paediatric Cardiology. European Journal of Preventive Cardiology 19 (2011) 1034–1065
12. Schickendantz et al. Sporttauglichkeit bei Kindern mit angeborenen Herzfehlern. Monatsschr Kinderheilkd 2012DOI 10.1007/s00112-012-2773-7

Intervention group =
15 children and adolescents aged 8-17 years with serious congenital heart disease.

Control group =
18 children and adolescents with similar diagnosis

No rehabilitation related complications or adverse effects were observed



12–week cardiac rehabilitation program

Follow up 6.9 ± 1.6 months post rehab.

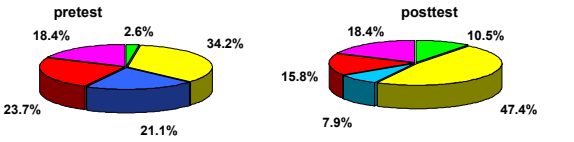
Rhodes et al. Pediatrics 116 (2005) 1339-1345,
Rhodes et al. Pediatrics 118 (2006), e586-93

Participation in specific supervised programs for the promotion of motor abilities can help to limit motor deficits and prepare and support the integration of children into their peer group

The participation in such groups is especially **but not only** recommended for patients with significant findings and complex heart defects

Children-heart-groups

A diversified perceptional and motor learning program - which motivate children and satisfy their need for movement, play and demand their creativity



Study group 38 children and adolescents aged 7-14 with diverse CHD

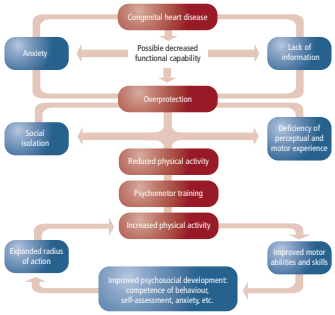
Intervention: 8 months (75-minute once a week) specific psychomotor training program

n = 38

MQ 116-130 = good motor development
MQ 86-115 = normal motor development
MQ 71- 85 = moderate motor disturbances
MQ 56-70 = severe motor disturbances
MQ <56 = below classifications level

Dordel et al. Deutsche Zeitschrift für Sportmedizin 50 (1999), 5-11

Figure 2: Compensation of Negative Consequences of Congenital Heart Disease by Means of Goal-orientated Improvement of Motor Development



Physical activity and sport participation in CHD-children

as soon as possible
beginning already in babyhood and pre-school-age

as normal as possible
participation in peers normal indoor and outdoor activities - in kindergarten - in school etc.

as much as possible
the children´s elementary and natural need for motor-activities should not be interrupted unless necessary because of danger of physical overload

In preschool children, the development of skills and even difficult coordinative tasks is of utmost importance.

A diversified perceptional and motor learning program - which motivate children and satisfy their need for movement, play and demand their creativity

In prepubertal children

a playful mixture of different age appropriate activity tasks focusing mainly on skills/coordination, but also carefully on flexibility and strength and endurance. During this period physical activity habits for later life are established.

Aerobic exercise in children with CHD

- the activity/exercise must be fun and interesting for the child.
  - jogging, or using stationary cycle is boring and children quickly lose interest.
- the program should include variety of aerobic activities focused on "modified" peers present leisure time activities like swimming, biking, inlineskating, kickbording scooter riding etc., as well as outdoor and indoor games with aerobic component
- **the goal in such programs is not necessarily physical training but rather improvement in physical activity and movement.**
- a successful program is aerobic in it´s nature as well as interesting to the child and based on perceptional and motor learning.

Improving strength performance in children with CHD

climbing, pulling, pushing, swinging, jumping, bouncing ect.

integrated in a diversified perceptional and motor learning program - which motivate children and satisfy their need for movement, play and demand their creativity

Exercise Training in pubertal children and after puberty

For **pubertal children**, other components of exercise play a more important role.
Social components like integration into a team or compliance to fixed rules are important.

After puberty, training can be similar to adults', focusing especially on strength and endurance

For all age groups, the most essential tasks to avoid a sedentary life style during childhood and to convince the child that participation in physical activity is fun.

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Review

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Recommendations for physical activity, recreation sport, and exercise training in paediatric patients with congenital heart disease: a report from the Exercise, Basic & Translational Research Section of the European Association of Cardiovascular Prevention and Rehabilitation, the European Congenital Heart and Lung Exercise Group, and the Association for European Paediatric Cardiology

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Recommendations for clinical practice

- Clinicians should be aware of the detrimental effects of inactivity and sedentary behaviour and should promote physical activity in children with CHD.
- Advice regarding appropriate levels of physical activity should be implemented in clinical consultations.
- Children with CHD should comply with public health recommen dations for daily participation in "60 min of moderate-to-vigorous physical activity that is developmentally appropriate and enjoyable, and involves a variety of activities.
- Moreover, they should perform <2 h/day of sedentary activities such as watching TV, using a computer, and playing video games.

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Recommendations for clinical practice

- Physical activity counselling should be a priority during every visit with a healthcare professional. The importance of daily activity should be emphasized and encouraged at all clinic visits.
- Healthcare professionals should encourage the patient (and their caregivers) to ask questions about their physical activity levels and should provide specific counselling to encourage physical activity …
- Clinicians should provide written recommendations (including restrictions and permissions) to both primary care providers as well as parents and patients regarding appropriate levels of physical activity and exercise.

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Recommendations for clinical practice

- Physical activity participation should be assessed regularly. For children, assessments of motor skills should be completed until the child has achieved all of the basic motor skills.
- The basic motor skills include not only walking and running, but more sophisticated movement patterns (e.g. hopping, jumping, leaping) as well as object manipulation skills (e.g. throwing, catching, kicking). Involvement of a physical activity expert may be indicated.
- Objective measurements of the patient's daily physical activity (versus self-report or proxy-report) should be considered and patients who do not achieve the recommended level of daily moderate-to-vigorous activity should be offered additional counselling or training interventions until an adequate level of physical activity is achieved and maintained.

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Thank you for your attention

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