

The Children's Heart Federation (CHF) is an umbrella body with 22 member organisations dedicated to helping children with congenital or acquired heart disease and their families in the UK and Ireland.

CHF provides information and support through its freephone helpline 0808 808 5000, open Monday to Friday and its website www.chfed.org.uk

We need support for the **LET'S GET MOVING** campaign from all sorts of people and organisations, including:

- ✓ Children and young people with CoHD and their brothers, sisters and friends;
- ✓ Parents and other relatives of children with CoHD;
- ✓ GUCHs (grown ups with CoHD);
- ✓ Sports teachers and coaches;
- ✓ Sports providing and promoting organisations;
- ✓ Health and social care professionals;
- ✓ Planners and policy-makers in national and local government;
- ✓ Members of support groups and other voluntary and community organisations;
- ✓ Funding organisations and individual fundraisers and volunteers;
- ✓ Media, PR and information professionals

To JOIN THE CAMPAIGN, please:

- ♥ Sign up on the **LET'S GET MOVING** page at www.chfed.org.uk
- ♥ Call 020 7422 0630
- ♥ Write to **LET'S GET MOVING**, CHF, 2-4 Great Eastern Street, London EC2A 3NW

We look forward to hearing from you!



A CALL TO ACTION
to include children with congenital
heart disease in PE at school and
to increase their access to
sport in the community

May 2009

Off the sidelines...

He sits inside and plays board games

Every school will have at least one child with congenital heart disease (CoHD)¹ – a malformation of the heart from birth. These children may have surgery several times during childhood and their condition and treatment often leaves them with some physical restrictions. However, **'there is a misconception that these children are very fragile, and thus they are often restricted from physical activity'** (Paediatrics December 2005).

Around a third of the parents who responded to CHF's *Survey of Experiences of Sport and Exercise for Children and Young People aged up to 19 with Congenital Heart Disease* felt that the school did not offer enough of the right type of sports or alternative activities for their child. In addition, there were several reports of children being left on the sidelines, both in PE lessons and school trips.

Cardiologist said not to limit her – that she'd know when she needed to rest

While teachers are clearly concerned about health risks, advice to parents from medical experts is usually that children know when to 'self-limit'. Most parents have received verbal advice from healthcare professionals about their heart child and sports, but many reported that there is a real need for written information and guidance on this subject.

She was excluded from the playground -- considered 'fragile' according to the head teacher

He cannot do swimming but has not been offered an alternative activity. He just has to sit out and watch other children swim

¹One in every 133 babies is born with a heart defect. That's 5000 babies every year – a further 1000 children acquire a heart problem in childhood because of an illness.

...and into action!

CHF has launched a campaign called **LET'S GET MOVING FOR HEART CHILDREN'S HEALTH** to enable children and young people with CoHD to:

- ♥ Participate to their fullest capabilities in school PE and school trips;
- ♥ Access a wide range of good quality sport and active leisure opportunities in the community.

CHF will be working in partnership with other individuals and groups on a range of initiatives designed to ensure that:

- ✓ Parents of children with CoHD and young people with CoHD know their rights in relation to access to sport and exercise at school and in the community;
- ✓ Individual Education Plans (IEP) for children with CoHD cover sports and exercise;
- ✓ Teachers feel confident about including children with CoHD in sport and school trips because they have received appropriate training and information;
- ✓ Healthcare professionals and voluntary sector information services provide accurate and accessible information about sport and CoHD;
- ✓ Providers of sport and active leisure in the community know how to encourage the involvement of people with CoHD.

Written advice would be helpful both as a reminder for my son and to give to the school

A heart child with obvious physical restrictions should be given an individual plan for sports and resources to enable them to be included in activities so that they can take part and feel normal