Endocardial Fibroelastosis

Other names that may be used for this condition are:
- EFE
- EMFE
- Endocardial Dysplasia
- Foetal Endomyocardial Fibrosis
- Subendocardial Sclerosis

Endocardial Fibroelastosis is a rare disorder that affects the heart. It is characterised by the thickening of the heart muscle resulting in progressive heart failure. This is caused by an increased amount of supporting connective tissue and elastin fibres. Endocardial Fibroelastosis can be primary or secondary due to a number of heart diseases that are apparent from birth. The disorder once occurred in approximately 1 in 5,000 births, but numbers have since declined for unknown reasons, possibly due to the introduction to the MMR vaccine.

Treatment of this disorder may include plenty of rest, medications to control congestive heart failure and other heart problems. Antiarrhythmics can help to maintain a normal heart rhythm. Anticoagulants may be used to help prevent blood clots forming. Diuretics may be used to help to remove fluids from the body. Surgical replacement of a heart valve may be required. As a last resort, a heart transplant may necessary for children with severe problems. Other treatment that may be offered is aims to provide relief for any symptoms and support in the care of the individual. Genetic counselling is recommended for those affected by this disorder and their families. The prognosis for those affected by this disorder varies greatly and is greatly dependant on whether heart failure occurs during early infancy. Unfortunately a third of children die in early infancy or at the onset of symptoms and another third develop chronic heart failure. However a third of children recover from the disorder completely.

This information is fully sourced and referenced, for more detailed information and references please contact CLIMB by email, letter or telephone.

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Climb National Information Centre for Metabolic Diseases

Climb Building, 176 Nantwich Road, Crewe, Cheshire, CW2 6BG, UK

Freephone: 0800 652 3181
Email: ir.svcs@climb.org.uk

Climb is the only charity in the United Kingdom that provides support on all Metabolic Diseases with links worldwide

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