

Moravian Women's Association - Home & Overseas Paper - June 2018

EHLERS-DANLOS SYNDROME

When my twin grand-daughters, Clara and Hannah, were little they were very supple and as they grew became good at sport, especially swimming and gymnastics and could contort their bodies and limbs with ease, such as joining their hands together, stepping through them and taking them right round over their heads to the front again. A party trick that was awesome to watch!

As they reached teen-age this started to become a problem, especially for Clara and they were both diagnosed with "hyper-mobility". Hannah suffered severe back pain but it was manageable and she is now a mother and was able to give birth naturally. Sadly Clara's has become much worse, with first her knees popping out of joint, then her hips and even her shoulders. She was recently diagnosed with EHLERS-DANLOS SYNDROME (EDS) type 3.

EDS is a group of disorders that effect connective tissues supporting the skin, bones, blood vessels and many other organs and tissue. Defects in connective tissue (stretchiness) cause the signs and symptoms of this condition, which range from mildly loose joints to life threatening complications. There is no cure for this, except intensive physio-therapy to strengthen muscles, and pain control.

It is genetic and I have researched into my grandparents descendent, 5 generations, and apart from my Uncle who was "double jointed" and used to amuse us with party tricks at Christmas I cannot find anyone else with EDS. However Clara will have many more genes in her system than I can possibly trace! An unsolved mystery?

(Incidentally my Uncle's condition saved his life in World War One when the plane he was piloting was shot down and he only managed to escape the inferno because he was so supple. It's an ill-wind that blows nobody any good?!)

My family are very grateful to the MWA Central Committee for allocating £500 to EDS research into possible cures and prevention for this very debilitating disease.

It is strange that in our small congregation at Baidon two families are affected by EDS. One adult and three children now young women, and the main symptoms are extreme pain and fatigue.

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