

March 26, 2010

Dear Labour and Delivery Nurse,

Have you ever seen a baby with bunions on its feet? Likely you haven't. If that should ever occur, however, please recommend a referral to a medical geneticist. The reason is that there's a good chance the baby has a disorder called **Fibrodysplasia Ossificans Progressiva ("FOP")**. We at the Canadian FOP Network are a group of families touched by FOP. We are writing to you because, as labour and delivery nurses, you will be among the first medical professionals to examine newborn infants.

FOP causes soft tissue swellings in which muscles, tendons and ligaments become progressively converted to bone (yes, you read that correctly). The ossification process typically begins in the head, neck, back and shoulders, later progressing down the arms and legs. Joints become fused, causing significant disability. Most cases of FOP are spontaneous occurrences with no family history.

It is extremely important that FOP be identified as early as possible, because the FOP disease process is accelerated by trauma to soft tissues. People with FOP need to take extra care to avoid traumas, even fairly minor incidents which wouldn't injure a typical person. **Trauma includes surgery, and such routine medical procedures as *intra-muscular injections***. Unfortunately, the soft tissue swellings of FOP, called "flare-ups", are frequently misdiagnosed as cancer, which leads to inappropriate and harmful medical treatment. In one extreme case several years ago, a 3 year old girl in the United States had her right arm and shoulder unnecessarily amputated before she was correctly diagnosed with FOP. There is no cure for FOP, and treatment options are limited and inconsistent. Surgery to remove bone formation is not recommended, because the trauma of surgery has a high risk of leading to explosive new bone growth.

The presence of the bunions is usually the first sign of FOP. Also, the great (big) toes may be angled inward, and may also be smaller than usual. An additional early symptom is thumbs which are clasped to the palm (though FOP wouldn't be suspected in the absence of the toe abnormalities). Apart from the toe and sometime thumbs signs, however, a baby with FOP will usually appear otherwise unremarkable. FOP flare-ups usually begin within the first few years of childhood, though may not occur until as late as the teen years.

The following photo shows the feet of a toddler with FOP, with characteristic toe signs present:



FOP is exceptionally rare, affecting only 1 in about 1.6 million people. Though FOP is rare, the consequences of inappropriate medical treatment can be disastrous for an affected person, which is why we seek to raise awareness of FOP.

If you wish to learn more about FOP, please visit the Canadian FOP Network's website at www.cfopn.org, or e-mail us at canadianfopnetwork@live.com. Additional information can be found at the website of the International FOP Association at www.ifopa.org.

Thank you for your time and consideration.

Yours truly,

Karen E. Munro
Vice-President, Canadian FOP Network