

# Fibrodysplasia Ossificans Progressiva Essay

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Fibrodysplasia ossificans progressiva also known as FOP is a one of the rarest, most disabling genetic bone conditions known to medicine. FOP causes muscles, tendons, ligaments, and other connective tissues to turn in to bone. Movement becomes limited in the affected areas of the body. People with FOP typically have malformed toes at birth, meaning the big toe is typically shorter than normal and abnormally turned outward in a position called a valgus deviation. Symptoms of FOP start to show up in early childhood. Most people with FOP develop painful tumor-like swellings also known as fibrous nodules. The fibrous nodules are visible on the neck, shoulders, and back. When a patient starts to generate new bone, what doctors call a flare-up; it causes tissue swelling and joint stiffness. Flare-ups may last as long as 6-8 weeks. Also during a flare-up the patients might experience low-grade fevers, this is mainly because fevers are part of an inflammatory reaction. In most cases, fibrodysplasia ossificans progressiva is missed diagnosed. One of the most common missed diagnoses is cancer because of the tumor like knots when the doctors go in to try to remove the "tumor" they cause more damage because flare-ups typically develop after a person experiences trauma to the body, such as a fall, small bump or even a small burse. Also illnesses, such as the flu may also trigger flare-ups. In one case of FOP they did so much damage that they had to remove the patient's arm. Experts estimate that the rate of misdiagnosis of FOP may be 80% or

higher.FOP occurs randomly and is not inherited. Experts believe that one cause of fibrodysplasia ossificans progressiva is born with mutations in the ACVR gene what provides the body with instructio..... middle of paper .....At that time physical therapy was recommended. Erin eventually learned how to roll over, sit up on her own, and walk all through physical therapy. However these milestones were significantly delayed and her balance was always off. Erin took a horrific fall off the couch and landed on her forehead. She was still swollen from the “allergic reaction” from the previous month. A CT-Scan showed no bone fractures but the goose-egg that had developed took months to go away. In 2008 she officially diagnosed with FOP.Ashley Kurpiel lives in Georgia. She was adopted when she was nine weeks old. Just before she turned 3 years old, she was misdiagnosed with cancer and her right arm/shoulder was amputated. Five months after her amputation she was correctly diagnosed with Fibrodysplasia Ossificans Progressiva, or more commonly known as FOP. She is the only amputee with FOP.

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