Rion

LIVING WITH PROGRESSIVE OSSEOUS HETEROPLASIA (POH)

his legs are stiffening with the extra bone growth, literally turning rock hard..!

"Rion is the only one in Ireland with POH and one of 100 in the world. They are trying to find a cure but it probably won't be in our lifetime…"

Rion is a very happy child.

Rion was born in 2011, I noticed that he had a very unusual marking on his leg so mentioned it to the doctor. He said that it was probably just a birthmark.

At his six week checkup the marking was worse, like a vein running all the way up his leg to his hip. The doctor then sent him to see a specialist doctor in Crumlin. Gebetic testing was conducted. They results indicated that Rion had an ultra-ultra rare progressive disease called progressive osseous heteroplasia (POH).

POH causes bone to grow under the skin deep into the muscles, ligaments, tendons, nerves and blood vessels. POH causes growth problems in the affected area, mobility problems and severe pain. Nothing can be done to help Rion in any way. Medication is the only thing.

They can't operate or remove any of the excess bone as it causes further progression of the disease. He can walk but only around the house. Falls cause new bone formation therefore we have to mind him. Rion uses a wheelchair for school and going out.

The extra bone pops through the skin at times, causing sores. Also his legs are stiffening with the extra bone growth, literally turning rock hard..

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