

Worldwide swim for FD/MAS 2019

Dear All,

My Background

I am 18 years old and was diagnosed with mono-ostotic Fibrous dysplasia in the right femur in 2012. At age 8, I broke the bone playing football and spent 6 weeks in a splint in bed followed by many months of recovery. The doctors could not explain how the strongest bone in the body could be broken clean through, so easily, playing football. This is because at the time they did not diagnose fibrous dysplasia, not even looking for an underlying cause. As a result, I relapsed in 2012 while running, developing a stress fracture that left me unable to walk. It was discovered that my bone had bowed outward. I was then referred to the Birmingham Royal Orthopaedic Hospital where a bone Biopsy confirmed FD. Following this, I had a plate and screws inserted into my femur to strengthen it and prevent further bowing. The metalwork was taken out after a year due to many complications. It was replaced by an osteotomy to straighten the bowed bone and I had an intermedullary rod inserted through the femur to strengthen it. During this whole time, I had numerous fractures in the same area restricting me to bed rest, only walking rarely and if so with crutches. This whole experience caused me to miss a total of around 2-3 years of school. This included missing more than half of my GCSE exam course with a pain in that area the majority of the time that could not be explained. I am now limited to a light jog for a few paces with no further activity. I was a very active child and have not run since 2012.

I had always held hope that after I had finished growing, the bone would fully heal, become normal and I would be able to continue with my life as always intended, as a very active person. This thought was one that comforted me and helped me stay positive in whatever I went through. In my most recent appointment I have been told that this will not be the case and that it is something that I am just going to have to live with. This whole experience has affected my life in an enormous way and despite going through all of this I consider myself very lucky that my case was not more severe, as I know it can be, and I am aware that people go through much worse.

Why take part?

The realisation that my FD is not going away has inspired and affected me in very profound way. This, backed up by the understanding that I am part of a larger community going through their own experiences has driven me to take matters into my own hands, ie: reducing my reliance on doctors and wanting to help others going through the same thing. This is why I wish to organise a global event to raise awareness and funds for Fibrous Dysplasia and McCune Albright Syndrome. Swimming has been the only form of activity

that I have been able to do to keep fit and therefore my idea was to encourage people with FD and MAS around the world to participate in a sponsored swim. In this way, each person will have their own personal reason for taking part while all sharing common experiences and one common goal.

I hope this event will also encourage people with FD/MAS to become more active, improving their physical health. Swimming is a non-weight bearing activity and many different strokes can be used and tailored to people with FD in different parts of the body so that they are able to participate to the best of their ability. Swimming is one of the best ways to keep fit and strengthen muscle without having an adverse effect on weak bone. People often use hydrotherapy, as I did, as a form of rehabilitation, and this may be the first step towards swimming. I loved going to hydrotherapy as it allowed me to walk in the water unaided, having previously been completely reliant on crutches. This inspired me to push harder towards the goal of recovery.

Swimming and staying active is especially helpful for maintaining a positive state of mental well-being, something that is of paramount importance with a chronic condition such as this. I know first-hand the effect this condition can have on one's mental health and for me swimming has helped a lot. My hope is that it can do the same for people with fibrous dysplasia across the globe so that they do not feel as though they are any less than anyone else, or alone. I hope that the FD/MAS community will be strengthened by having people with FD take part in the swim, a community upon which people with the condition can rely on when needed for support later.

As part of the event, I am training for a 10km swim. I am aware that people will have varying degrees of mobility but even one person swimming one length that wasn't previously thought possible would be an incredible achievement, making this whole event a success. I have written to several Fibrous Dysplasia organisations across the world to see if more people would take part to help achieve this goal.

I know first-hand that this condition is extremely difficult to live with, especially as a child and people simply do not know about it. This is where we can make a difference. Raising awareness of FD/MAS will encourage all to learn more about the condition and provide more money and support for scientists that conduct research into the field developing our understanding of the condition. We can do all this so that in the future those with FD/MAS have a better experience and quality of life.

How we can do it

I will be setting up a website so that people can write their own stories, explain why they want to participate and share how their training is progressing, to encourage, support and motivate everyone

taking part. A place the public can view and where people can donate. I am situated in Malvern in Worcestershire UK and think that next year we could have a select few venues across the country for people in the UK where they can swim together in one great event.

I will be working on making the website by the end of the year with hopes of having the swim next summer around August time so there's plenty of time to prepare! Any help in any way in terms of logistics for this would be much appreciated and let's see how we can all do our part to make it work. I will be in touch with updates but if you're interested in taking part or have any ideas please just message me through Facebook or on worldfdswim@gmail.com . I know it's a big ask but we can make this happen!

I will be at the UK annual FD conference at Birmingham Children's Hospital on November 17th, hope to see you there. Thank you all so much.

Nish 😊