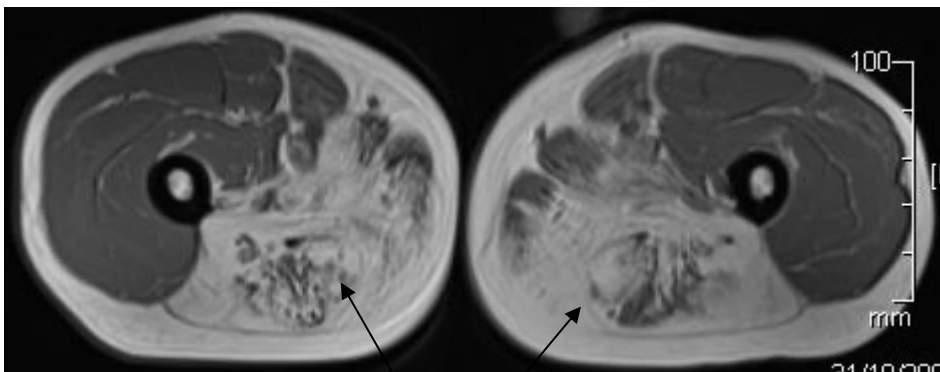


Good Vibrations

I was exploring Pompe, an island I found myself on, and came across a bridge which reached out into the distance, the bridge vibrated when I put my foot on it and I quickly removed my foot. A woman appeared and smiled, I asked if the bridge was safe and where did it lead to, she said he didn't know but he had thought the bridge would take me to where I wanted to go but no one had ever tried it from the island...

When I was diagnosed with Pompe over a year ago I thought that I would be given all the information about rehab, diet etc. How wrong could I be? I lost over a stone in weight under my own guidance which has definitely helped and still awaiting any guidance on a high protein diet.

Rehab has been mainly non-existent mainly because funding and the knowledge base very limited. My condition could be described as good for a Pompe patient. I can walk (waddle) over 3 miles and can swim a reasonable distance. My main weakness is around the trunk which effects bending and jogging /running is a distant memory. Eight months after my diagnosis I had an MRI scan of my trunk and leg muscles. The images took me aback at first, but you realise why the muscles are so weak. I asked whether the muscles shown in white were beyond repair and the best way to start improving their condition, once again a deafening silence greeted me and I was on my own again.



Fatty atrophy hamstring muscles

I started to look at different ways I may improve my condition. I first contemplated using electronic stimulation but after some research I thought the generated movement would be too aggressive on the ruptured muscles cells. My attention went to Whole Body Vibration (WBV) which seemed to tick all the right boxes. Firstly, there is no big stretching of the muscles and secondly it activates all the muscles fibres in the area you are trying to target (unlike conventional training). You go to an introduction class first and the main poses which are squats which target legs, bum, groin and lower abs and press ups, you hold eight poses for 1-2 minutes; the session lasts for about 15 mins. The work done is by basically holding the position static while the platform oscillates linearly at ~40Hz/sec; the actual movement is roughly 3mm. I do find holding the position hard and can only manage half a squat. The hamstrings, glutes and groin do tend to feel tight post exercise but this is my aim. The main problem is there is no information or trials on

how this form exercise would affect my muscle condition and you get a lot of conflicting advice. I started off by going once a week then quickly increased to twice. I tried three times a week, but this was too much.

I have now had 34 sessions and the benefits are beginning to show, in my 6 monthly ERT review my 6 minute walk distance improved by 15%. They also noticed that my ability to turn was much better controlled. It will be interesting to see the results in October. I am hoping the improvement does not plateau like the ERT tends to on its own. I feel that the synergy of WBV and ERT is a major factor and hopefully continues to enhance my physical improvement. I am keeping a log of all my sessions and relating how I am feeling. I look at this as a long term plan and I suppose if successful will offer other GSD patients another option. I have approached most of the charities and Institutions for funding but as yet due to insufficient data on the beneficial effects I have had no joy. I would experiment with trying to have more sessions but less poses per session.

However, this would be very expensive and ultimately would involve having my own machine at home which would cost approx £5K. Unperturbed though I will continue walking across the bridge!