Jaime’s Testimony

When you are young, you take walking for granted, you take breathing and laughing for granted, rolling over in bed and waking to be able to stand and eat for granted. You just ... you just do. Then suddenly those things become a task, a giant mountain. You suddenly realise... your life is on hold.

Your literal life breath is on hold. External things, pressures of money, debt, friendship, relational, can be in part forgotten or distracted for a time, but when it's your very being, your breath, your heartbeat... you can't.

I was a musical theatre performer, dancer, actress and lover of life, at 14 years old life was fun and exciting, until one day it wasn't. I had a bout of Shingles, and suddenly things started to spiral, spiking fevers, joints became sore and swollen and red. My heart started to hurt, and I ached. The GP thought I had glandular fever..... every month. Then anxiety, then ME ..... it wasn't long before I started to think maybe the years of bullying were taking their toll on me and this was it, I was going crazy.

But life started to slow, quickly. Good days, bad days and days, when, days when I would rather I wouldn't waked up and see my peers running around, my dancing friends dancing and my stage friends acting. Because I just didn't hurt, life hurt. Life hurt. It hurt to watch others living when living was hard.

For the next few years, this is where I remained in a spiral of GP appointments that did not believe me. Until one day, and a change of GP who believed me, at the age of 18, they took blood and within 24 hrs I was in hospital. We had only been married just 6 months, newlywed at the age of 18, I was hopeful this would be a new beginning, but my body followed me. Darn, it, why could I not leave this behind on my wedding day, but it didn't work like that. Honeymoon was taken from us by the sickness we did not know we were fighting. We tried our best to make the most of our little honeymoon in Stratford upon Avon UK, but it was ruined by pain.

We vowed to ourselves one day we would do it again and do it well. We still wait for that vow.

The hospital found raised markers in my blood that were off the scale. Very quickly I was being MRI, scanned and every bit of me looked at. Consultants thought I had Lupus and this was where we sat as a newly married couple, in the department being told how worried they were about my kidneys, heart and levels. It was terrifying. We had just bought our first home, trying to hold down a job, my husband also. We wanted our little house so much. But, within 6 months, I lost my job to this sickness, Gary followed suit to care for me and then within months, the judge repossessed our little house, my little house. As we closed the door and started to rent a world of rentals opened to us for the last 25 years this has been our life our story, from one place to the next. Not having any place to call "ours'. Because of this disease, that took my little house.

We soon were told it wasn't wise to have children, that I would likely miscarry or put myself at risk and that was just not possible for me.

One thing this disease didn't know was that despite it all, It had tackled a girl with stubborn faith and she wasn't giving in without a fight although every day since then has been just that ... " A fight"

Over the next 10 years, we worked on the diagnosis of Connective tissue disease and we lived with it, battling the good, the bad and the ugly as a young couple, we defied the odds and despite the struggle, we had two beautiful kids to the consultant's surprise, then a third. It was tough, but I wanted to be a mum more than anything. After our 3rd child, the children had started to display symptoms that were too familiar to look at, Great Ormond Street stepped in and here began another massive spiral of strength.

In 2007 when our 3rd was just born, I was seen in UCHL in the London autonomic unit and Bristol and Cambridge and Surrey and after 100 plus appointments and phone consults, they tilted me, on a test and saw what had been in my mind and the consultants all along.... POTS (Postural Orthostatic Tachycardia Syndrome) and Ehlers-Danlos Syndrome. But, not just in me... but all my kids.

I was shattered, we were shattered. Broken. This couldn't be my story, this couldn't now be "our story"

My baby, my little house was gone, and now.... my real babies were suffering too. My hospital visits became our hospital visits as we sat in room after room, with physio and consultants hearts being scanned kidneys being looked at and fatigue bursts.

In the early days, our home felt more like a hospital ward, with one laid on the sofa with heat bags, one with painkillers, another crying as their feet hurt in the night, and I had to find the strength to be a nurse and mum when I needed a nurse and a comfort blanket, but they needed me.

Being a patient and a nurse is hard, to anyone that has done this, I hear your silent tears, your deep breaths against your pain. You are a hero to your child and I know you need someone to be your hero too.

The last 11 years have been the hardest, but as said I am a fighter and 11 years ago, we decided amidst the fight we would do something to claw back the life we had dreamt of. One day with my ballet shoes hung on the end of my bed, I prayed. I felt in my heart a voice, "Put your ballet shoes on and just believe only" It was there a dream was born. I may not be able to dance and act right now, but I could teach, I could inspire, I could use what was in me and help those who couldn't afford classes to do what I once loved to do. I could still give back.

In 2012 my husband and I started to teach a group of young people in Guildford Surrey, for donation only, over the last 11 years we have continued the dream and vision and over this time I have taught thousands of young people and adults Musical theatre and produced over 26 productions, short films, presentations and outreaches. Despite it all, you have to kick back. Labels, can't define who you are called to be, who you are created to be. Limitations are not impossible, they are just reasons to find another way, a solution a way to make a change.

Has it been hard, yes, has it hurt yes? Has it been painful..... YES.

But, oh so worth it, to see the looks on children's faces when they achieve standing on stage for the first time when they take their bow and the audience roars. When you get to hug a child through a bullying episode at school, encourage them to get up in class and dance and by the end of it, they feel a somebody because you chose to ignore the aching joints, and the banging heart and invest in someone else.