Resource

#ThisIsJIA by Gail Molyneaux

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This is JIA.

I was diagnosed with Systemic Juvenile Idiopathic Arthritis (sJIA), also known as Still’s Disease, when I was just five years old back in 1973. It’s a rare and debilitating form of Juvenile Idiopathic Arthritis (JIA) that has profoundly impacted my life journey.

The first signs were bronchitis-like symptoms that escalated into high fevers, swollen and painful ankles. After misdiagnosis and ineffective treatments, months of uncertainty followed with tests for various infections before finally concluding it was Juvenile Rheumatoid Arthritis (now called JIA). This marked the start of my lifelong relationship with rheumatologists and other medical professionals.

Initial treatment, as it was limited at the time, involved steroids, anti-inflammatory drugs, and a diligent exercise regime encouraged by my supportive dad through small bribes despite my pain. The inflammation was difficult to control, requiring ankle callipers that led to teasing from other children. However, my family ensured I could still enjoy activities like hiking and camping, sometimes carried on my dad's back.

At age seven, my health critically worsened when I contracted the rare Reye's Syndrome, landing me in a coma with an uncertain recovery after my heart stopped beating. Thankfully, the doctors' commitment and my family's support helped me survive, though with persistent memory retention issues.

My care later transferred from my local rheumatologist, who had been very supportive, to a specialist in Juvenile Rheumatoid Arthritis, down south. She played a pivotal role in my life with her dedicated treatment approach of anti-inflammatories, steroids, antibiotics and exercises. This allowed me to eventually go into remission for a couple of years until a polyarthritis flare-up followed after stepping on something sharp.

Over the years, I underwent various treatments like disease-modifying drugs, physiotherapy, hydrotherapy, and multiple surgeries. My education was impacted by long absences, but I persevered through home tuition, supportive friends, and cherished horse-riding as an escape. I looked like everyone else once on the horse.

My partner and I lived our early life together to the full, and despite me finding it difficult to manoeuvre on and off a bike, we were keen motorcyclists. The systems engineering career I loved was cut short by redundancy due to frequent hospitalisations, but I was determined to work and started a secretarial services business. Infact, despite immense challenges in my life including a long, difficult journey to pregnancy, an ankylosing spondylitis diagnosis, multiple hip replacements, and continued joint damage, I have remained resilient through tremendous determination and family/friend support.

Maintaining open communication and mutual respect with my consultants has been invaluable, as has voluntary work and cherishing motherhood. Confidence issues stemming from an unconventional childhood linger but have improved significantly. Multiple joint damage and pain continue to govern and impact my life. I would love to ride a bicycle with my daughter and husband, but limited movement and pain hinder this. I love gardening but it doesn’t love me, and I’m restricted in what I can do. Fatigue is also a huge issue. I continue to undertake a lot of voluntary work due to the impact JIA has had on my career and work.

I’m now awaiting further shoulder replacement surgery while writing a book about my decades-long journey with sJIA and chronic pain in the hope of helping others affected by this disease.

With resilience and love from my support system, I strive to live life to the fullest despite the obstacles Still’s Disease presents.

My advice for anyone living with JIA is to just try things and never give up.