Amid focus on curing illness, concern over treatment of disabled in society

I can still remember each second of that day just before Christmas when everything changed.The happy family lunch, then the seizure suffered by my tiny new daughter, her eyes rolling and little limbs flailing. The nice paediatrician telling us gently she had “profound brain damage,” then carrying her with tears in my eyes through crowds of festive shoppers.

The next months and years are harder to recall, a blur of dark times later identified as the mourning period that parents in such cases endure. There were batteries of tests, endless scans, the same ceaseless questions as she was prodded, probed and wired up to weird machines. But there were none of the expected signs of brain damage, nor any clues over her condition from the doctors searching for a diagnosis.

So it was good to see the announcement last week of a £300m package of public and private investment for the 100,000 Genomes Project, a Cambridge-based research initiative to sequence genomes of NHS patients. This is a significant step into the promised brave new world of medicine, with genetic code deciphered to discover, treat and even predict illness. It will also boost a related project focusing on children such as mine whose disorders evade conventional diagnosis.

Read the full, original story: Will my disabled daughter have a place in this genetic wonderland?