In an age of genetic healing, what happens to those too old to find cures?

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.

Four years ago we finally got the diagnosis: a genetic disorder called CDKL5 discovered a decade after her birth. We were told she was among 200 recognised cases worldwide, although numbers grow all the time. I found this revelation after so long strangely unsettling; it was a reminder also that too many people are defined by their disabilities rather than their personalities or skills.

This is not to quibble with any woman’s sacred right to choose, merely to highlight the casual acceptance that disabled lives are second-rate and can be discarded as too burdensome. Some people, even doctors, say such things explicitly; this is the backdrop facing people with disabilities even before birth. Now we enter the age of genetics, which offers such hope for advancing healthcare but has also sparked a new form of eugenics, with scientists talking of eradicating disabilities at birth from the human condition.

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