Whitney’s story as told to
www.dailymail.co.uk/health/article-6039473/7-mothers-lost-thriving-teenage-daughters-ALS.html

Judy Baird, 53, from Salt Lake City, Utah, lost her daughter Whitney to ALS in 2008 – she was just 22 years old and like many of the moms who have lost their daughters to ALS, she struggled to get a diagnosis.

Her symptoms began in May 2007 with weakness in her legs, but she didn't tell her parents. At the time she lived with Judy, her stepfather Dwayne, now 63, and her siblings Dustyn, now 34, Chelsey, now 30, Lacey, now 28 and Torey, now 24.

Whitney moved to Austin, Texas where she worked on a service mission for the Mormon Church, so she had limited contact with her family. In the November she fell down the stairs and hurt her neck.

By the following May 2008, she was having difficulty pulling her arms above her head and on a visit home, Judy ensured that she visited a doctor.

'It was typical that Whitney never complained about the initial fall,' said Judy. 'She wouldn't have wanted to worry us but with hindsight, it was likely the ALS that caused the fall.

'When she came home I persuaded her to see a doctor as it was clear she was struggling to do up her shirt and put her hands above her head – I remember when she hugged me she couldn't raise her arms.

'We visited with several doctors, orthopedic and neurologists but no-one had an answer. We had a family acquaintance who had ALS and I remember thinking that Whitney's hands looked like his, so I researched it.

'What I read was terrifying but I also read how incredibly rare it was, so I pushed it to the back of my mind.'

In July 2008, a neurologist at the University of Utah Hospital in Salt Lake City told Whitney: 'You have the symptoms of ALS but you are far too young to have it.'

'I couldn't agree that it wasn't ALS,' said Judy. 'I always believed it could be but there was no definitive diagnosis. Yet with no diagnosis there was also no treatment so we were stuck.

'She started physical therapy to strengthen her arms but ultimately it didn't help. As her breathing deteriorated and her swallowing, she refused a ventilator and a feeding tube because she knew it was going to prolong the inevitable and I believe that she didn't want to live like that – somehow, she was at peace with what was happening to her body.'

Two days before she passed away in August 2008 – just over a year after her first symptoms – Whitney was finally diagnosed with ALS.

'I remember the last day she was alive,' said Judy. 'We have a large family and we knew the end was coming, so we all crowded into her room so she felt the love in there.

'I climbed into bed with her and I told her a million times how much I loved her. She said that she was afraid because she didn't know how to go – so I told her that none of us know how to die.

'She was so brave and her passing was peaceful, tender and sweet because she firmly believed in God but also devastating – losing her happened so quickly.'

Because the FUS gene wasn't discovered in 2008, Whitney wasn't tested for it until later when her tissue samples were taken and they tested positive.

'The FUS gene is so fast,' said Judy. 'It takes its victims so quickly and while I would have done anything for more time with Whitney, I'm glad she went quickly because she was suffering so much and it was hard to see that.

'I grieved for a long time but now I've met the other moms and Project ALS, I am so angry that this happened to so many other young women. When Whitney was sick I was told it was rare but now I think more girls are being diagnosed and we have to find out why.

'Now I am involved in this small movement I feel positive and I am healing. Of course I will never get over losing Whitney but at least her story is making a difference in the fight for the cure or to find a way to slow this down.

'I will be forever grateful to Project ALS for its unending work into ALS research. Whitney would be very happy that this is happening and none of these children's deaths have been in vain. The thought of other families suffering drives us all.'